

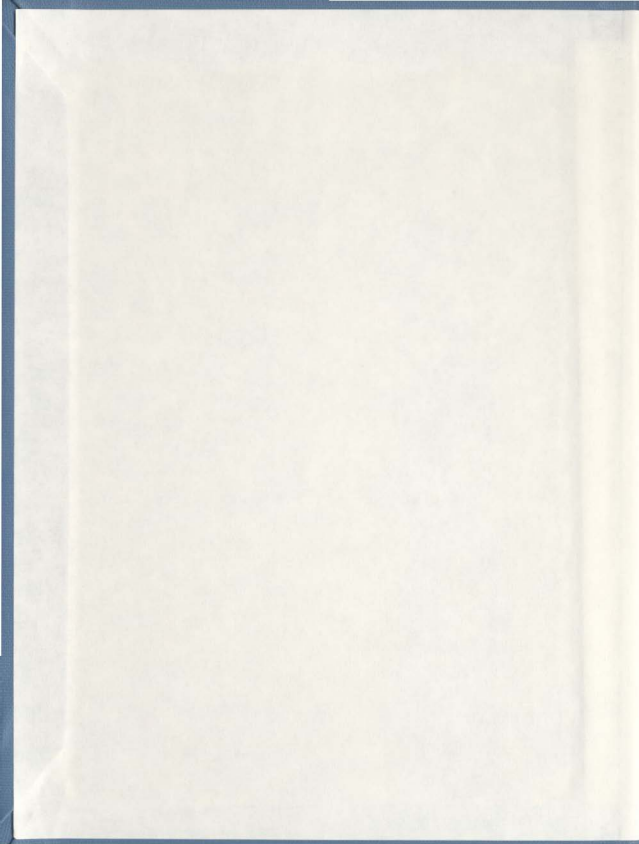
THE PSYCHOSOCIAL DEVELOPMENT OF ADOLESCENT
SIBLINGS OF CHILDREN WITH SPINA BIFIDA

CENTRE FOR NEWFOUNDLAND STUDIES

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CATHERINE M. ROYLE



The Psychosocial Development
of Adolescent Siblings of
Children with Spina Bifida

by

Catherine M. Royle

A Thesis Submitted in Conformity with the Requirements
for the Degree of Master of Nursing
at Memorial University of Newfoundland

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ABSTRACT

A qualitative research study was undertaken to describe the developmental experiences of adolescents who have a sibling with spina bifida and to examine the impact of having a physically disabled sibling on the development of such adolescents. The developmental tasks of Duvall and Miller (1985) provided a conceptual framework for exploring the developmental experiences of adolescents and sorting and analyzing the data.

Eleven adolescents, with the approval of their parents, participated in the study which involved tape recorded interviews. The guided interview process was utilized to obtain descriptions of the adolescents' experiences related to their development.

The analysis revealed that the adolescents were in the process of achieving the developmental tasks appropriate for their age group. The experience of living with a child with a physical disability did have some impact on specific developmental tasks. Many of the adolescents demonstrated a maturity in development of specific tasks and this may be related to the experience of living with a child with a physical disability. Having a sibling with spina bifida has an impact upon six major areas during adolescence: 1) family responsibilities, 2) parental relationships, 3) sibling interaction, 4) school, 5) friends and peers, and 6) personal maturation.

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CHAPTER 1

There is an increasing number of children with disabilities surviving infancy due to increased medical technology and treatment. Correspondingly, there exists a social trend to integrate these children into the community. As more of these children are being raised in their own homes with their own families, there is a heightened awareness that there are implications for the child, the family, and the community at large. Both advanced medical technology and increased social awareness have resulted in disabled children and their families being identified as a population of focus in today's health care system.

The birth of a child who will be physically disabled may be a crisis event for a family. It may be the beginning of a lifelong commitment to caring, coping, and adjusting to stress for all those involved with the child with the disability (Minde, Hackett, Killou, & Silver, 1972; Featherstone, 1981; Seligman, 1983). The presence of a physically disabled child in the home places many demands on the entire family, yet, the parents have traditionally been identified as those most in need of support, information, caring and other forms of nursing intervention (Poznanski, 1973; Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975; Rankin, 1979; Berry & Zimmerman,

1983; Brooks-Gunn & Lewis, 1984).

Consideration of siblings of children with physical disabilities is often secondary to the needs of the affected child and parents. Moreover, when the needs of these siblings are considered, they are often assumed to be related to the responses of the parents and child to the disability. Factors such as parental neglect, increased parental expectations, increased responsibility and/or demands of the physically disabled child have been described as influencing the siblings response to the disabled child (Taylor, 1980; Simeonsson & McHale, 1981; Siemon, 1984; Trahd, 1986; Seligman, 1987).

There is a paucity of information available about the implications of having a physically disabled brother or sister on the development of siblings, and, therefore there is no consistent approach to meeting the needs of the siblings. Consideration of the psychosocial development of the adolescent sibling of physically disabled children also has important implications for the further development of related nursing theory and subsequent nursing practice.

Problem Statement

Family-centered care is a philosophy which encourages nurses and other health care professionals to consider the effects of health, illness or disability on all family

members and on the family unit. It is the researcher's belief that family centered care is not fully implemented in today's nursing practice when caring for families with a physically disabled child. The focus of care is usually directed towards the affected child and his/her parents with the sibling subgroup often overlooked. A review of the literature revealed that there is a lack of documentation describing the implications of having a physically disabled brother or sister on the development, psychosocial or otherwise, of siblings of any age, including adolescence. These implications need to be identified so that the needs of the adolescent and the family unit can be met.

The presence of a physically disabled child has implications for family functioning and dynamics (Nevin, McCubbin & Birkebak, 1984; Longo & Bond, 1984; Romney, 1984; McCormick, Charney, & Stemmler, 1986). Subsequently, this may have implications for the development of individual family members such as adolescent siblings.

Adolescence can be described as a transition period between childhood and adulthood. It is often considered to be one of the most stressful of the developmental stages as the adolescent is adjusting simultaneously to critical physical changes and psychosocial issues. Factors which may influence the individual's adjustment to adolescence include the social world and life experiences

of the adolescent (Nelms & Mullins, 1982). The struggle for independence versus dependence and for self identity versus group identity are among the conflicts which are paramount during this stage of the life cycle.

The importance of validating the adolescent's feelings is an essential dimension of providing health care to this population (Lohner, 1987). Feigon and Gronner (1982) suggest that "children approaching adolescence seem to be a prime target (for membership in a group project for siblings of handicapped children) as they are working through their own identity and may need outside feedback regarding the realities of their situation and a therapeutic understanding of their feelings" (p.27).

Rothery (1987) suggests that as siblings are "struggling with their own developmental issues, they are also struggling with the nature and extent of their sibling's disability"(p.21). Adolescents who reside in a home with a physically disabled child may have many unique experiences that influence their psychosocial development. Exploration of these experiences related to their own development should provide insight into the needs of the adolescent. The needs of these adolescents could then be met through anticipatory care and health promotion strategies.

The concept of health promotion has relevance to this

study. The literature illustrated that siblings of physically disabled children have concerns related to their feelings, their health, and their relationship with their disabled sibling. Concerns regarding the future for themselves and their sibling have also been expressed (Powell & Ogle, 1985). The promotion of health knowledge and behavior, based on appropriate developmental assessment, would assist nurses in addressing the concerns and needs of this population.

In this study, the sample was selected from families who have a child with spina bifida. Spina bifida is one of the most common causes of congenital physical disability in Newfoundland and Labrador. From 1967 to 1976 there was an estimated total of 162 children born with myelodysplasia in the province. In 1980, the incidence of spina bifida in Newfoundland was 1.4 per 1000 births (Squires, 1982).

Spina bifida can be defined as a neural tube defect in which there are varying degrees of physical deficit. Some children experience no difficulty with ambulation while other children are paraplegic and confined to a wheelchair. While there is a high degree of hydrocephalus associated with spina bifida, insertion of a ventroperitoneal shunt often prevents a reduction in mental capabilities. McCormick, Charney, and Stemmler (1986) identified the limitations of activities of a group

of children with spina bifida. These included difficulties with walking, toileting, play activities, bathing and dressing. The parents generally perceived the child's health positively. These children required the collaborative interventions of, and treatments prescribed by, many health professionals. As a result of these interventions, "families contend with many disruptions in family life and face the challenge of raising a child with special needs" (Macedo & Posel, 1987, p. 56). Inherent in the challenge of raising a child with a physical disability, for many parents, is the challenge of raising other non-disabled children at the same time. Knowledge of the siblings reactions and responses pertaining to living with a child with a physical disability would be beneficial in counselling the parents in child rearing practices.

In directing research efforts towards the siblings of physically disabled children, the scope of family centered care would be improved. Information is needed to plan appropriate care to meet the needs that are identified and specific to this unique population.

Purposes of the Study

The immediate research purposes of this study are:

1. to describe the developmental experiences of adolescents who have a sibling with spina

bifida.

2. to examine the impact of having a physically disabled sibling on the psychosocial development of the adolescent.

The ultimate purposes of this study are:

1. to increase the conceptual knowledge base regarding the impact of having a physically disabled sibling on the adolescent.
2. to facilitate the development of a framework for assessing the developmental achievements of these adolescents.
3. to provide nurses and other health professionals with information that will assist them in the selection and implementation of effective nursing strategies, based upon accurate assessment of the developmental status of the adolescent sibling as a client.

Specific Research Questions

A research study exploring and describing the psychosocial development of adolescent siblings was undertaken. The use of appropriate developmental tasks is one way of exploring the psychological and social development of an individual or groups of individuals.

The specific research questions are stated as follows:

1. How do the adolescent siblings of physically disabled

children describe their own psychosocial development?

2. How is the psychosocial development of adolescents influenced by having a sibling with a physical disability resulting from spina bifida?

Conceptual Framework

The psychosocial development of adolescence provides the conceptual basis for this study. The framework selected for exploring the development of adolescents is that used by Duvall (1977) and edited by Duvall and Miller (1985). Duvall (1977) ascribes "developmental tasks" to each stage of the life cycle. Developmental tasks are defined as "tasks that arise at or near a certain time in the life of an individual, the successful achievement of which leads to his happiness and to his success with later tasks" (p. 167). Developmental tasks relate the physical growth of an individual to newly acquired skills or accomplishments. Thus, identification of developmental tasks for each stage of the life cycle is based upon physical maturation and is influenced by the cultural environment of the individual. Developmental tasks are further described by Duvall (1977) as a "thrust from within the individual to develop in such a way (by modifying present behavior) as to attain a desired goal... it is a growth responsibility that the individual assumes

for his or her own development as he adapts to his life situation" (p. 169).

The developmental task of adolescence (teenagers) as described by Duvall and Miller (1985) include:

1. Accepting one's changing body and learning to use it effectively.
2. Achieving a satisfying and socially accepted masculine or feminine role.
3. Developing more mature relationships with one's age-mates.
4. Achieving emotional independence from parents and other adults.
5. Getting an education for present and future roles in life.
6. Preparing for marriage and family life.
7. Developing the knowledge, skills, and sensitivities required for civic competence.
8. Establishing one's identity as a socially responsible person. (p. 242 - 243)

The developmental tasks of adolescence are unique to this stage of the life cycle. It is essential that the adolescent achieve these tasks successfully in order to adapt to further stages in the lifespan. The tasks of adolescence represent an integration of the physical changes in one's body and the psychosocial environment in which these changes occur.

There are many factors which influence the individual's ability to attain specific developmental tasks. Of primary relevance to this study is the influence of the environment. The presence of a physically disabled child alters the environment of the family, thus influencing the development of all those within the family. This environment, in turn, influences the roles and functions of the family unit and its individual members.

According to Howe (1980), sociocultural factors heavily influence the age by which the adolescent developmental tasks are undertaken and accomplished. Considering the presence of a physically disabled child in the family as an alteration in the social or cultural environment, then it would follow that this presents unique implications on the development of the adolescent sibling.

Definitions

For the purposes of this study, these terms are defined as follows:

Adolescence - is a transition period, a time between childhood and adulthood. It is defined by physiologic, psychologic, and sociologic factors as well as chronological age. It is the "physiologic

period between the beginning of puberty and the cessation of bodily growth. It is a time of increased emotional and cognitive maturity. Adolescence generally begins between ages 12 and 14 years and continues on the average until 18 to 20 years" (Pillitteri, 1987, p. 494). For the purposes of this study, adolescence will be defined as those between 13 and 18 years of age.

Developmental Task - tasks unique to a certain time in an individual's life cycle, the successful achievement of which facilitates the individual's adaptation to further life events.

Disability - permanent loss of a physical or sensory ability; can be the result of a congenital or acquired defect.

Myelomeningocele - the most serious variety of spina bifida. There is a "wide defect in the posterior neural arches, with a protrusion of meninges and neural tissue" (Stark, 1977, p. 5).

Sibling - a brother or sister who resides in the same dwelling on a permanent basis. The brother or sister is a biological relative or a legally adopted child.

Spina Bifida - a congenital condition which results from a "defective fusion of one or more posterior vertebral arches which may be accompanied by protrusion of the meninges, spinal cord or nerve roots beyond the normal limits of the spinal canal" (Stark, 1977, p. 4). It results in various degrees of physical disability (ie. various degrees of bowel and bladder incontinence, various degrees of lower extremity paralysis).

CHAPTER 2

Literature Review

In qualitative research, it is appropriate for the investigator to "critically examine previous research and to selectively use this work" (Field & Morse, 1985, p. 35). The literature was used as a general guide to facilitate an open, but informed, approach to the current study. Several areas in the literature were reviewed in order for the researcher to examine the scope of the research problem. It should be noted that this did not provide any answers to the questions concerning the development of the siblings of physically disabled children. Rather, the purpose of this literature review was to illustrate and define the areas of concern that have already been addressed through research. These areas are: 1) the significance of sibling relationships between healthy children on development; 2) the disabled child and the family; 3) siblings of disabled children.

Two limitations of the literature were identified. A review of the literature did not reveal any research studies which investigated the implications of having a physically disabled sibling on adolescent development. In most of the studies where siblings have been identified as the population of interest, the results and discussions are primarily based on reports and observations made by

parents, teachers, or other health professionals. Rarely has the sibling been both the subject and the focus of research relevant to themselves.

A further limitation of the literature pertinent to this area is the inconsistent use of the term "handicap" which has been applied to the presence of physical, mental, and/or developmental disabilities. Unfortunately, this distinction is rarely made in the title of the report. The term "handicap" is often used interchangeably with the term "disabled". Both "disabled" and "handicapped" have also been used to reflect the status of children with chronic illness and their families. The lack of a unified conceptualization of terms such as "handicapped", "disabled", "chronic conditions", and "chronic illness" results in difficulty in interpretation of research findings in this area for nursing practice.

The Significance of Sibling Relationships Between Healthy Children on Development

To understand the effect of a child with a physical disability upon sibling development, it is imperative to recall the intrinsic factors which influence the relationships between healthy siblings. A brief overview of the literature relevant to the relationships between healthy siblings is presented in this section. While this is not an exhaustive review of the literature, it does

highlight factors which may need to be considered in the study of the relationships between siblings when one of the children has a disability.

Age differences, sex and maternal references to the child were several factors described by Dunn and Kendrick (1982) as influencing the sibling relationship particularly following the birth of the second child. Lamb (1982) outlined some of the important roles siblings have in the socialization of children. They are the most regular playmates to both older and younger siblings. Older siblings represent role models of interesting activities and behavior.

Castiglia (1989) suggested that sibling relationships influence the socialization process of the children; "This means that how the older child reacts to the younger sibling affects not only the older child's future interaction abilities but also the future interaction abilities of the younger child" (p. 52).

Bank and Kahn (1982) recognized that the bond between two siblings can be positive or negative and can change over time. Yet, the strength of the bond lies in the sibling relationship whereby "one gets the sense of both being a distinct individual and of constancy through knowing a sibling as a predictable person" (p. 15).

The nature of the sibling relationship is reciprocal. Factors such as age, sex, birth order, and family

circumstance often determine, in part, the roles and responsibilities siblings often assume with and for each other. The influence of the sibling relationship on psychosocial development changes throughout the different periods of the lifespan. Bowerman and Dobash (1974) concluded that there was considerable variability in the amount of affect that adolescents had towards siblings. These authors suggested that: 1) females were more likely to have favorable feelings than males, 2) the same sex sibling was preferred, and 3) the adolescent generally felt closer to an older sibling than to a younger one. The study of sibling relationships is also essential because this relationship influences personal satisfaction. "The kind of relationships the adolescent has with siblings will influence very strongly the level of personal satisfaction he obtains from living in the family during the early years" (Bowerman & Dobash, 1974, p. 48). The sibling relationship also affects other interrelationships within the family, such as relationships between individual children and parents or grandparents.

The Disabled Child and the Family

In recent years, there has been much written on the effects of children with varying physical conditions, diseases, and the prognoses of such, on the family unit.

Similar research findings have been reported when the family includes a child with a physical disability, a chronic illness, or chronic condition. Regardless of the physical condition of the child, the emphasis of the research or study is on the specific concerns of the family.

Romney (1984), considered the implications on family development and parenting when a child with a congenital defect was born. This author reviewed theories pertaining to pregnancy and parenthood as developmental phases and as a crisis. She suggests that family life may be disrupted and this may be an "overwhelming experience for parents, siblings, extended family and friends" (p. 10). Nursing interventions suggested to facilitate the adjustment of the family included encouraging the parents to see the infant, providing information, adapting hospital routines, and encouraging communication among the family.

Family functioning and family dynamics in relation to the presence of a disabled child were discussed by Berdie and Selig (1981). These authors identified concepts, based upon a review of family systems theory and the special experiences of families with children who are disabled, for understanding family dynamics. The six concepts were 1) the reverberation effect which, in systems theory, explains the effect of the disability on both the nuclear and extended families; 2) homeostasis in

that families need to feel a sense of control and order in their lives and this may be disrupted by the presence of a child with a disability; 3) change as stressor in that both positive and negative changes may affect the homeostasis that the family is trying to maintain; 4) maintenance mechanisms and patterns of interaction are established by families in an effort to maintain homeostasis or to deal with stress; 5) the source and influence of familiar coping strategies are unique and need to be assessed individually for each family, and 6) the effects of stress and crisis on patterns of interaction suggests that stress precedes crisis and the family's previous experience with stress and crisis will affect their response to the current crisis of dealing with a child with a disability.

Several researchers (Brandt, 1984, Kazak & Marvin, 1984; Schilling, Gilchrist, & Schinke, 1984) have documented the concepts of coping, crisis and the need for social support for families with disabled children. Brandt (1984) described the importance of using the Personal Resource Questionnaire and the Norbeck Social Support Questionnaire in assessing the social networks of these families and provided a guideline for assessing the family's network support. These guidelines included assessing the presence and accessibility of family resources and determining how each family member utilized

these resources.

Schilling, Gilchrist, and Schinke (1984) presented an overview of several studies, related to the concepts of personal coping and social support, identifying the difficulties experienced by parents of disabled children. These difficulties are related to the presence of stress and conflict within a family which can be increased by ineffective coping. A structured group approach for these parents to utilize their personal coping strategies and social supports was proposed.

Kazak and Marvin (1984) studied the differences in families with and without a disabled child (spina bifida) in relation to stress and social support. Parents of 56 children with spina bifida and parents of 53 children without a disability completed a social network interview. The parents also completed the Langner Symptom Checklist, the Parenting Stress Index and the Dyadic Adjustment Scale. Rank order and correlational statistics were applied to the data. The findings supported the presence of higher levels of stress in the families with disabled children but the families were found to have successful coping strategies. The importance of identifying positive family strengths and existing adaptational patterns into clinical interventions is emphasized.

The impact of a child with spina bifida on the family was assessed through a research study by McCormick,

Charney, and Stemmler (1986). The characteristics of families that may be more vulnerable to the impact of caring for disabled children were studied. The findings indicated that family characteristics (i.e. number of adults in the home, unmarried parent, or lower maternal education) and the child's functioning had a greater impact on the family than did the clinical diagnosis. The impact on the family was related to such specific influences as the child's activities of daily living, perceptions of the child's health and socioeconomic factors.

Caring for a child with a disability may also influence the child-rearing practices employed by parents although few studies have validated this. King (1981) investigated the child-rearing practices of parents of a child with a chronic illness and a well sibling. Mothers and fathers each completed two Child-Rearing Practices Questionnaires (CRPQ), one related to the child with the chronic illness, and the other related to the well sibling. Using a multiple analysis of variance (MANOVA), no significant difference in child-rearing practices were found related to the health status of the child.

When one individual has been isolated for investigation of concerns regarding the disabled child, it is primarily the mother. Brooks-Gunn and Lewis (1984) assessed maternal interactions with their disabled

infants. This study investigated the influence of the infant's chronological age, mental age and disabling condition on the mother's interaction with her infant. The results indicated that the mothers of developmentally delayed children for other reasons exhibited more responsive behavior than mothers of children with either Down Syndrome or cerebral palsy.

An attempt to predict coping behaviors of mothers of disabled children was made by Friedrich (1979). A stepwise multiple regression analysis of data collected on 98 mothers of children with a wide variety of disabling conditions, not specifically identified in the study, indicated that marital satisfaction was the best overall predictor of coping behavior. The child's residence and sex were also considered to be significant predictors. Mothers of children who were institutionalized experienced more stress than mothers of children who resided at home. Similarly, mothers of female children affected with a disability experienced more stress than mothers of male children.

The psychological distress of mothers of disabled children was investigated by Breslau, Staruch, and Mortimer (1982). The scores on two indices of psychological distress were compared for a group of 369 mothers of children with a variety of different conditions to a group of 456 randomly selected control subjects. It

was found that, while the type of disability did not account for the level of distress, the more dependent the child, the greater was the mother's distress.

Disabled children and their siblings do not exist in isolation. They are both members of the broader family system. Thus, consideration must be given to the fact that factors which have been isolated as having an impact upon the family as a unit or the parents as a subsystem may also have implications for the siblings themselves.

Siblings of Children with Disability

The presence of a child with a chronic condition, mental, and/or physical disability has an impact upon the family, including the non-affected siblings. However, the nature of the impact and the implications of specific conditions or disabilities on healthy siblings of various ages are inconclusive. To date, the literature which was reviewed primarily reflected anecdotal stories of life with a disabled sibling. Many authors presented an overview of past research findings whose results have been either inconclusive or conflicting, yet implications for practice are often based upon such data (Simeonsson & McHale, 1981; McKeever, 1984; Skrtic, Summers, Brotherson & Turnbull, 1984). Research has been directed towards identification of stressors, responses and coping

mechanisms of families and parents.

McKeever (1984) reviewed selected literature available from 1960 until 1982 pertaining to siblings of children with various chronic disabilities or health problems (i.e. diabetes, mental retardation, cystic fibrosis and spina bifida). The children's responses to "illness" in their sibling that have been reported included 1) increased likelihood of behavioral and academic problems, 2) negative self-esteem and 3) increased somatic problems. There was no distinction made regarding the concerns or responses of siblings of children with specific physical disabilities. Therefore, one cannot assume that the siblings of a child with a physical disability such as spina bifida would experience similar responses.

Skrtic, Summers, Brotherton, and Turnbull (1984) analyzed research on siblings of severely disabled children within the context of the family as a whole. These authors categorized research findings in terms of its relevance to family functions and family structure. Based on the analysis of the research reviewed, these authors suggested that siblings can be required to fulfill any or all of the roles necessary to complete family functions, including economic functions, physical care, and socialization. It was noted that during adolescence, there is a heightened awareness of "differentness" of the

disabled sibling, which may be associated with embarrassment, a sense of loss, increased responsibility for the child or a perceived need to compensate for the disabilities of the child.

Simeonsson and McHale (1981) discussed studies related to the relationship between siblings when one is disabled. Identity problems, physical demands, psychological expectations, and maturity of attitudes and behavior were considered to be representative of the areas of concern for those involved with the healthy siblings of disabled children. Several factors were identified as influencing the sibling relationships. These included socioeconomic factors, sex, birth order, family size, severity of the disability, parental attitudes, and religion. These authors suggest further research is needed involving disabled children and their siblings.

McHale, Sloan, and Simeonsson (1986) further investigated the relationship between healthy children and their autistic, mentally disabled or non-disabled brothers and sisters. The mothers completed behavior rating scales and both mothers and the healthy children described the sibling relationship. The sibling relationships were rated positively by both the children and their mothers. However, mothers of non-disabled children rated the sibling relationship more negatively than did the mothers of children with a disability.

Faux (1986) compared the relationship between congenitally impaired children and their siblings with the relationship between healthy siblings. Semi-structured interview guides were utilized to obtain qualitative data from the children. Mothers completed the Sibling Inventory of Behavior scale. The majority of the children with siblings who had a congenital impairment described positive relationships but were significantly more protective of their sibling than were the siblings of healthy children.

The importance of informing the siblings of chronically ill or disabled children about the condition was stressed by Seligman (1987). A review of the literature by this author revealed that there are both positive and negative consequences to being the sibling of a disabled child. The negative reactions included 1) a lack of communication between siblings and parents, 2) feelings of isolation, and 3) increased responsibility. The sibling responses included 1) anger, 2) resentment, 3) guilt, and 4) a threatened identity. The development of positive characteristic traits such as compassion and tolerance were reported by Seligman to be some of the benefits of having a disabled sibling.

Research pertaining to sibling response to chronic childhood disorders was reviewed by Brett (1988). The literature reviewed was examined in terms of crisis and

stress, family systems and coping frameworks. The major conclusion made in the report was that "siblings of chronically ill or disabled children are indeed a population at risk for future maladjustment" (p. 53). The above study also described implications for preventative nursing care.

The unique circumstance of a healthy child with a physical disability, such as spina bifida, within the family has been the source of research into family functioning and to a lesser extent, sibling relationships and development. Nevin, McCubbin and Birkebak (1984) investigated the concepts of stress and coping in families with a child with spina bifida. The focus of the study was on parental stress factors or crisis events and subsequent coping mechanisms. Parental strategies for coping include "efforts to maintain the family's integrity and optimism, securing social support, maintaining the members and child's self-esteem, and psychological stability and understanding the child's medical condition through communication with other parents and medical staff" (p. 13). The impact of spina bifida on the siblings was not specifically addressed, but may be inferred only from the discussion of the interventions aimed at the family.

In a study by Roberts (1981), the degree of family functioning in a family with a child with myelodysplasia

was closely related with the family's satisfaction with family functioning. The target of this study was the family unit, and little reference was made to the siblings.

There is a paucity of significant research exploring the implications of physical disabilities, including spina bifida, for non-disabled siblings. In one of the landmark studies of siblings by Tew and Lawrence (1973), no difference was found in the intelligence scores of siblings of children with spina bifida when compared to a group with non-disabled siblings. In the same study, teachers were asked to complete an adjustment scale for the siblings of the disabled child. The results indicated that the siblings of children with spina bifida were four times more likely to have maladjustment problems in school, including behavioral and cognitive difficulties. The mental and physical health of the mothers was also investigated and a high stress level was noted. This study is limited in that the ages of the siblings are not identified as a significant variable; nor are the siblings themselves the source of information.

Breslau, Weitzman and Messenger (1981) studied the psychologic functioning of siblings of disabled children. In this study, the disabled children were diagnosed with either cystic fibrosis, myelodysplasia or multiple disabilities. The diagnostic categories of the disabled

children showed no significant effect on the siblings' scores on a personality inventory. Also, little relationship was found between the mothers' perceptions of caring for a disabled child and the amount of attention given to the siblings.

Pinyard (1983) examined the perceptions of school aged siblings of children with myelomeningocele. This is one of a very few studies in which the siblings as well as the parents are the source of data. The findings of this study revealed that the siblings had concerns about the disabled child and that their parents were not always aware of such concerns. Findings in this study suggested that the siblings' responses to having a disabled brother or sister had an impact on various aspects of their own development (play, school behavior, and peer relationships). Pinyard concluded that sibling adjustment may be dependent upon the family coping strategies, and that further research is needed to determine what constitutes effective coping strategies for siblings as well as families.

Harvey and Greenway (1984) compared the self-concept of physically disabled children and their siblings. Three groups of sibling pairs were investigated; one group of disabled children attended the same "normal" school as their sibling, the second group of disabled children attended a "special" school while their siblings attended

a different school. The third group was a control group comprised of healthy, non-disabled sibling pairs. Self-concept assessment scales were administered to the children. The results indicated that the siblings of the disabled children who attended a "normal" school obtained lower self-concept scores than the control group. The authors suggested that the presence of the disabled child in the local school may be "the critical factor in terms of the effect of the handicap upon the non-disabled sibling" (p. 282).

Kazak and Clarke (1986) specifically studied stress in families of children with myelomeningocele. The self-concept of the siblings was identified as a possible source of stress in the family. Findings indicated that having a disabled sibling does not necessarily have a negative effect, and that a higher self-concept was found in children of larger families. The authors suggest that the presence of "additional non-disabled children in the family provides for more diversity of role models and also reduces the load of responsibility on any one child" (p. 226).

The effects of having a developmentally delayed sibling (cause not identified) on normal children was examined from the parents perspective and observation by Scheiber (1989). The Nursing Child Assessment Teaching Scale (NCATS) was used to observe and assess the parent-

child interaction in seven families each with a developmentally delayed/disabled child and a 'normal' child. Based on the data collected from a small sample , the findings indicated that the families used diverse methods for problem-solving but that similar home environments were provided for normal children and their developmentally delayed brothers and sisters. More attention was given to the delayed child but the authors suggest that this may be related to the cues given by the delayed child and the ages of the children.

There is a lack of conclusive evidence regarding the implications of having a physically disabled sibling, regardless of the cause, on the psychosocial development of other siblings. One cannot assume that the siblings of physically disabled children respond in the same manner as siblings of children with chronic or life threatening illnesses or mentally disabling conditions. The nature of the disability and the general health of the affected child may play a specific and unique function in determining the development of the siblings. There is a need for further research exploring the development of healthy siblings of children with physically disabling conditions.

In summary, the literature indicated that siblings of physically disabled children are a population of interest to many researchers and a population which requires

further study, particularly by health care researchers. Inconsistencies have been reported in the findings of different research studies. There have been no studies found which explore the experiences of adolescent siblings; nor have there been any studies which attempt to examine the development of this population. It is the purpose of this study to increase the knowledge base so that more comprehensive family centered care may be provided.

CHAPTER 3

Methodology

An exploratory, descriptive approach was used in this qualitative research study. This approach is consistent with the nature of nursing and the nature of the research question. Stephanics (1974) described the "essence of nursing as having perspective into the client's world as he is experiencing it" (p. 128). The qualitative process reflects and complements this belief. Filstead (1970) stated that qualitative methodology "advocates an approach to examining the empirical social world which requires the researcher to interpret the real world from the perspectives of the subjects of his investigation" (p. 7). Similarly, Leininger (1985) viewed the goal of qualitative research to be fully documenting and interpreting whatever is being studied "in particular contexts from the people's viewpoint or frame of reference" (p. 5).

The use of a qualitative research approach facilitated the use of siblings themselves as primary data sources. In most of the past research, parents and teachers, not siblings, have been the sources of information. It is essential to obtain in-depth data which describes and explores the siblings' experiences.

The Population

The sample for this study was obtained from a

population of adolescents who were members of families in which there was a child who had previously been diagnosed with spina bifida (generally myelomeningocele). The criteria for inclusion in the study were as follows.

The participants will:

1. be adolescents who are between the ages of thirteen (13) and eighteen (18) years of age.
2. have a sibling who has been medically diagnosed with spina bifida and who is currently experiencing a physical disability.
3. not have a diagnosis of a mental or physical disability.
4. be living at home with their parents and the physically disabled sibling.
5. have parents who are able to verbally communicate in the English language.
6. provide their consent to participate in the study and agree to the use of a tape recorder during the interviews.

Sampling

The sample for this study was obtained with the assistance of two organizations that provide information and services to families with a child with spina bifida. Potential study participants were initially identified in a non-random order by two resource persons, the President

of the Newfoundland and Labrador Association for Spina Bifida and Hydrocephalus and the Nursing Outpatient Coordinator of the Children's Rehabilitation Center in St. John's (see Appendices A & B). The nature of the study and the criteria for study participants was carefully explained to these individuals. They were asked to identify and contact families who met the inclusion criteria and to obtain consent for release of their names and telephone numbers to the researcher (see Appendix C, Release of Name Form).

Following an examination of their respective files, a total of 22 families were contacted by the resource persons. Of these, seven did not meet the criteria as the siblings were not between the ages of 13 and 18 (inclusive). The age of the sibling was unknown to the resource persons at the time of the initial contact. Two families did not wish to participate in the study. Two families initially expressed interest in the study and gave consent to be contacted by the researcher. The parents were given information about the study to discuss with the adolescent and were to call the researcher but did not return the call of the investigator. Therefore, these families were not pursued for inclusion in the study. Eleven adolescents, with the approval of their parents participated in the study. The subjects all were approached initially through their parents. It is not

known what effect this method had on willingness of the subjects to take part in the study.

The Setting

The setting for the data collection was the choice of the adolescent and the family. It was felt that giving the adolescent the choice of the setting would facilitate confidentiality and security in sharing their experiences with the researcher. For most, it was the mother who suggested the place for the interview, and this was agreed with by the adolescent.

The researcher requested that the family make as few (if any) interruptions as possible to avoid distraction during the interview. Six of the interviews took place in the adolescent's bedroom with the door closed. Two interviews took place in the living room, one in the dining room and one in the family room. For these interviews, the mother assured privacy by amusing the other children in another part of the house or by taking them outside to play. One interview took place in the evening at the researcher's office at the request of the adolescent for the convenience of the family.

Ethical Considerations

It is imperative to consider the ethics of any investigation involving adolescents who are technically

considered minors in the legal system. Thus, careful precautions were taken to protect the rights of the study participants.

The proposal for the research study was approved by the Human Investigations Committee at the School of Nursing. The proposal was also presented to the organizations involved and permission was given for the resource persons to make the initial contact with the families. Letters were sent to both of the organizations explaining the study and requesting assistance in locating the families (see Appendices A & B).

Following the acquisition of the names and telephone numbers, the researcher contacted each family to arrange a time to evaluate further suitability of potential subjects for inclusion in the study, provide a letter of explanation (see Appendix D), discuss the study, and obtain informed consent from the parents.

The parents (in this study, the consents were all given by the mothers) were required to give the formal consent for their son's or daughter's inclusion in the study. The adolescents were each asked for their written consent to reinforce their status as the primary subject of the study, and to emphasize their ability to make decisions regarding their own contribution to the study. No parent or adolescent refused to sign the consent form.

To obtain informed consent, the investigator spent

time explaining the study to both the parents and the adolescents. The need for privacy was carefully explained as were the issues of anonymity and confidentiality. The parents and the adolescents were reassured that no data would be published that would lead to the identification of the adolescent. The researcher explained that while the adolescent may recognize his or her own remarks, it was unlikely that others would. Some adolescents expressed concern regarding who would be hearing the taped information. It was explained that the researcher and the typist, who was transcribing the tapes, would be the only people who would listen to the tape recorded interviews. The participants were advised that the information and experiences described by the adolescents would be reported in general, with no names connected to specific examples.

All data that were collected which may have identified the adolescent or the family (both on the tapes and in the transcriptions) were held in strict confidence during the analysis and reporting processes. All identifying data were destroyed at the completion of the research project.

The parents and the adolescents were also advised of the researcher's role in completing these interviews. The researcher was frequently asked by the parents about her nursing career and her interest in families with a disabled member. Thus, the researcher perceived her

acceptance by the family as that of being a nurse. Therefore, it was felt important to explain that her role at the present time was primarily to ask certain questions and to discuss certain topics with the adolescent. Given the nature of the research process of this study, the researcher could have become an audience to information that would indicate the need for intervention (Robinson & Thorne, 1988). If this situation arose, the parents and the adolescent were advised that the researcher would not provide that intervention but would recommend appropriate follow-up.

The adolescents were given the option of stopping the interview at any time. The participants were also advised that they were under no obligation to answer all of the questions and that they had the right to refuse to answer questions. No participant asked that the interview be discontinued while the tape was in progress, but when the tape concluded, two of the participants indicated that they would like to stop the interview at that time. One of these permitted the researcher to take notes regarding his responses to two final questions and these were added to the transcription of that tape. The second subject had answered all the questions and further questioning was not considered necessary at this time. Several of the participants indicated both verbally and non-verbally that there were questions that they would prefer not to answer

and these wishes were respected.

Data Collection Procedure

The collection and analysis of data were facilitated by the use of tape recorded interviews with each of the adolescent participants. The use of a tape recorder was considered to be the most effective method to ensure accuracy of data by eliminating researcher bias and recall error. Consent for the study and use of the tape recorder was obtained from the parent and each adolescent. Most of the participants indicated that they were familiar with the use of a tape recorder either through school or through social activities and none opposed the use of the tape recorder during the interview. Prior to each interview, the parents were asked to provide demographic data pertaining to the ages, sex, and birth order of the children in the family (see Appendix F).

The adolescents were told that the researcher had prepared a tentative list of questions to be asked during the interview to ensure that certain areas were covered. They were told that the questions would not be asked in a specific order and that the researcher might ask questions not on the guide depending on the information given by the participant. All participants asked to see the types of questions that they would be asked. Most of the adolescents read through the questions, occasionally

making comments regarding the relevance of particular questions for themselves. It was at this time that several of the adolescents requested that specific questions pertaining to one particular topic not be asked. In each instance, these questions were related to sexuality.

A mixture of semi-structured and open ended questions were incorporated into a guided interview, a technique described by Field and Morse (1985). A guided interview is useful when information is required about a specific topic, ie. developmental tasks, but the responses cannot be anticipated. The use of the guided interview "ensures that the researcher will obtain all information required (without forgetting a question), while at the same time permitting the informant freedom of responses and description to illustrate concepts" (Field & Morse, p. 67).

The concept of the guided interview was expanded in this study to encompass the partially structured interview as outlined by Wilson (1985). This type of interview begins with an outline of topics (therefore is guided) but both the researcher and the study participants are free to "deviate from the prepared agenda and introduce thoughts or observations that are particularly relevant to their personal perspective as the conversation unfolds" (p. 382). In this research study, deviations were limited to those introduced by the study participants. The

researcher commented on these statements in relation to their relevance to particular developmental tasks.

Interview techniques (commenting, reflecting, and countersuggestion) as suggested by Faux, Walsh, and Deatrick (1988) were employed during the data collection process. Questions were posed from the least threatening to the more threatening (and from general to specific) to allow for the development of rapport between the researcher and the participant.

Throughout the interview, techniques such as the use of commenting or reflecting on the adolescent's response and the use of countersuggestion were used to determine response validity. To help reduce participant anxiety and to gain additional data, action questions were posed to the adolescents prior to being asked "feeling" questions. For example, The participant would be asked " what did you do when ...?" before being asked how they felt about that particular experience.

The primary interview with each adolescent consisted of both semi-structured and open ended questions. The semi-structured questions were guided by the developmental tasks as outlined in Duvall and Miller's conceptual framework. The open ended questions facilitated the adolescents' description of events, circumstances or other information that is related to their achievement of developmental tasks. An interview guide is outlined in

Appendix G. The researcher endeavored to explore all areas in the first interview, but not necessarily in the order stated. If the adolescent described a particular event, or circumstance, the relevance of this to his or her developmental tasks was explored at that point in the interview.

During each interview, the researcher also documented non-verbal communication cues (ie. facial expression, hand gestures) to augment the verbal communication that was being tape recorded. The researcher also briefly noted each area as it was explored during the interview to ensure adequate coverage of the selected areas as outlined on the interview guide in Appendix G.

At the conclusion of the first interview, each participant agreed to be contacted for a second interview if the researcher felt that there were other questions that needed to be asked. Following a review of the first interview of each of the study participants, a second interview was scheduled with two participants to correct any omissions of the first interview, to clarify responses as needed for validation purposes and to further explore any specific areas of development that were significant in the first interview. The second interview with these participants was brief, unique, and original. Because the purpose of the second interview was to reflect and expand upon the content of the first interview, it was

inappropriate to devise an interview guide for the second interview.

This overall method of data collection was perceived to be successful in eliciting responses from the adolescents. Many events, feelings, and concerns were described by the participants. Comments such as "I've never told this to anyone" and "it's good to have someone who wants to talk to me" were indicative of the positive response demonstrated towards the research.

Data Analysis

Following each interview, the tapes were transcribed into written documents. A description of the non-verbal cues was integrated into the written document as they occurred during the interview. The researcher reviewed all original tapes, their corresponding transcribed documents, and notes written throughout the data collection and analysis. As each interview was completed, it was transcribed and reviewed, allowing the researcher to explore new questions in subsequent interviews if required. While the initial data collection took place within a two month period, the ongoing data analysis took place during data collection and continued for another six months.

The management of the large amounts of data collected (approximately 1000 pages of transcribed data) was

facilitated by the use of The Ethnograph (Seidal, Kjolseth, & Clark; 1985), a computer package designed to organize and sort large volumes of data. This program was particularly relevant for use in that the researcher was responsible for the decision making regarding the coding and analysis of the data (Webster, 1988). The program facilitated data analysis in that the data was presented with numbered lines allowing the researcher to assign codesets to various combinations of lines. The researcher then entered these codes for each interview into the computer. The program was then able to sort and print the codes as requested by the researcher.

The responses of the adolescents were coded, analyzed, and categorized in terms of their relevance to each of the developmental tasks. Initially each segment was coded with words or phrases which reflected the content of that segment. This codeword was then compared to each of the developmental tasks and categorized appropriately.

The process of analyzing each segment for codewords served several purposes: it helped to avoid researcher bias in that the researcher did not attempt to "fit" segments into specific developmental tasks and it allowed for further in-depth analysis of the data. Thus, analysis was not limited to only the achievement of developmental tasks but permitted the researcher to examine other ideas

expressed by the participants.

As the data analysis proceeded, it became obvious that there were codes present in the data that were not being accounted for in the developmental tasks. Therefore, the final list of codes identified exceeded those that were specifically related to the developmental tasks as identified in the conceptual framework. A total of 70 codes were identified representing categories and subcategories of the eight developmental tasks and other additional categories not specifically isolated from the developmental tasks. These coded segments were then organized by the researcher into categories representing each of the eight developmental tasks. Additional categories which were significant to the study, related to the experiences of being the adolescent sibling of a child with spina bifida, were also isolated for discussion.

The analysis resulted in the description and examination of the responses within the eight categories representing the developmental tasks and/or the experiences of being the adolescent sibling of a child with spina bifida. The responses within each category were analyzed for frequency, consistency of responses, similarities and differences. The researcher was also interested in examining the influence of having a sibling who was physically disabled on each of the developmental tasks. For example, if an adolescent discussed how having

a brother or sister with spina bifida affected thoughts about marriage or family this was identified as having an influence. All segments of the interviews that made reference to the affected sibling were thus analyzed separately.

Reliability and Validity

The reliability and validity of the responses of the adolescents are assumed when the adolescents themselves are providing the data. Reliability of the data is enhanced because the adolescent has a personal investment in the project. Time was spent in establishing rapport with each adolescent, and in determining their previous use of the tape recorder or of sharing their experiences with interested others. The opportunity to express themselves was generally greeted positively by the adolescents. However, each interview with each study participant was individually examined for consistency of responses to similar or related questions. Inconsistent responses may not indicate a lack of reliability, but rather, may reflect the adolescents' uncertainty in meeting specific tasks. Inconsistent responses were not found in the analysis of each of the interviews.

Validity of the researcher's interpretation and analysis of the data was also examined. The researcher requested that another individual, familiar with the

qualitative research process and the content of the research topic (ie. developmental tasks of adolescence), review transcripts of tapes at random and assess the coding scheme. There was no incongruence between the researcher's interpretation and the reviewer. Congruence between the independent reviewer's and the researcher's interpretations of the data enhanced the validity of the study findings.

CHAPTER 4

Results : Developmental Tasks

The results of this study will be presented in the next two chapters. In this chapter, the experiences and reports of the participants will be described using Duvall and Miller's framework for each of the eight developmental tasks. In the next chapter, the influence of living with a sibling with spina bifida on the psychosocial development of the adolescent participants in this study will be explored and discussed. First, the demographic descriptors of the sample will be reported.

Demographic Descriptors

The demographic data used to describe the sample was obtained from the parents prior to the interview. Much of the same information was actually reported in the interview with the participants. The findings of this study are based on a sample of 11 adolescents between the ages of 13 and 17 years of age at the time of the interview. Seven of the adolescents were female and the remaining four were males. The sex and ages of the adolescents are presented in Table 1.

Table 1

Age and Sex of Participants

	<u>Age</u>					
	13	14	15	16	17	Total
<u>Sex</u>						
Female	2	1	1	2	1	7
Male	3	0	1	0	0	4

						11

Of the 11 participants, six were between the ages of 13 and 14 years and for discussion purposes were grouped as the "younger adolescents". The remaining five participants were between the ages of 15 and 17 years and were therefore regarded as the "older adolescents".

Three of the adolescents were members of two children families and were therefore the only non-disabled child in the family. Of the remaining eight families, there were four families with three children and four families with more than three children.

The birth order of the adolescent in relation to all children in the family was determined. Four of the adolescents were the oldest children, four were middle children and three were the youngest children in the family. Age relationship between the adolescent and the child with spina bifida was also determined and is presented in Table 2.

Table 2

Age Relationship Between Adolescent and Sibling with Spina Bifida

	<u>Age relationship to sibling</u>		
	Older	Younger	Total
<hr/>			
<u>Sex</u>			
Female	5	2	7
Male	2	2	4
<hr/>			11

There were five female adolescent and two male adolescent participants (total of seven) who were older than their sibling with spina bifida. There were four participants (two male and two female) who were younger than their sibling with spina bifida.

Of the 11 participants, four (three females and one male) were of the same sex as their sibling with spina bifida; two of these adolescents were older and two were younger than their siblings with spina bifida.

The Developmental Tasks

In describing their experiences as adolescents, the participants in this study were describing the achievement of age appropriate developmental tasks. Intensive analysis of the data revealed significant information about each of the eight developmental tasks as outlined by Duvall and Miller (1985). In this section, the analysis of the results of the interviews will be presented in

reference to each of these developmental tasks. In the next chapter, significant factors related to being the adolescent sibling of a child with spina bifida will be isolated for further presentation and discussion. The use of direct quotes from various participants will highlight these discussions.

Task 1: Accepting one's changing body and learning to use it effectively.

The majority of the adolescents interviewed were reluctant to specifically discuss areas concerning personal physical development and sexuality. In fact, adolescents requested that they not be asked specific questions in this area. Some of the adolescents were able to describe characteristics of their own physiques and did compare themselves to their peers. Puberty was mentioned by seven of the participants but defined by only two. Discussions on health revealed that the participants viewed health as being distinct from disability. Learning to use one's body effectively through learned physical skills was also discussed.

When asked to describe their own physical maturation, many adolescents used descriptors such as tall, short, fat or skinny. Physical maturation in terms of sexual development was avoided or addressed in nonspecific terms. One younger female stated that she had not yet noticed any

changes in her own body but that one of her friends was "developing really fast". Another younger female stated that she noticed the "usual changes" in her body but did not elaborate further except to state that this made her feel "more grown up, people think I'm older". The older females generally observed the changes occurring within themselves and did compare themselves to their friends, but admitted that they did not discuss this topic with their friends; nor did the adolescents discuss this with their parents or their siblings. Of same sex pairs of siblings, none of the adolescents compared themselves to their older or younger siblings. Male participants avoided discussions in this area and made only general remarks regarding the size and shape of their bodies.

Neither satisfaction nor dissatisfaction with the changes noted as their bodies matured could be conclusively interpreted from these adolescents. Those who described themselves as "developing the same as my friends" or who described themselves as being taller than their friends could be perceiving their own development positively, whereas those who described themselves as being "too skinny" or "too fat" may have been expressing some dissatisfaction.

Two of the participants observed differences in the development of males and females. One girl described the differences in terms of height. She noted that she was

"as tall as the boys" and another girl observed that "guys notice girls are developing differently, they're supposed to". Both of these participants indicated that the differences in development did not change the relationship among heterosexual groups of friends.

Puberty, itself, was defined by only two adolescents. One younger teenager said that "puberty means that you grow up and you're getting older and you're more matureyou look different, you act different and you're expected to do more". One older teenager stated that puberty is "when your body starts to change and it makes you more mature". Four of the adolescents indicated that sexuality issues, including puberty, were addressed in school but at various levels. Only one adolescent asserted that he would like to learn more about puberty and could ask a relative or teacher about this.

As a group, these adolescents possess basic concepts of health and awareness of health promotion practices. They attribute their knowledge of health primarily to school courses and were able to describe lifestyle behaviors which influenced their own health. Health was often distinguished as being the opposite of illness. One younger teenager stated that she determines her health "by the way I felt, if I felt OK". Alternatively, sickness was described as when "I don't feel good, I feel tired all the time, I get crabby". A male adolescent simply stated

that health was "not being sick." An older adolescent defined health as " the condition you're in, like how you feel."

The adolescents all agreed that their siblings with spina bifida were healthy. One girl described herself as "being sicker, like stomach sick or getting the flu" more frequently than her sibling. The presence of a physical disability was not perceived as a criterion for determining either health or illness. One adolescent, whose sibling experienced repeated hospitalizations related to his spina bifida, indicated that he was "sick once when he went in (hospital) but he's not sick now". Other adolescents described how their siblings required hospitalizations, particularly for surgery; but never referred to the sibling as being ill at that time.

With respect to maintaining their own health, the adolescents described practices such as eating a nutritional diet, exercising, avoiding people with colds, wearing warm clothes, not abusing medications, and not smoking. Nutrition and exercise were the most common health maintenance practices identified and these were also related to personal appearance as well as health. Several female participants specified that they were "watching what I eat" or "exercise because I don't want to get too big."

Personal practices which promoted one's development

and acceptance by others were also described. In addition to maintaining health, only two participants, both male, identified risk taking behaviors for themselves. One admitted to smoking, a practice that his parents were aware of and the other described himself as "a little bit crazy" when taking physical risks with certain outdoor activities. Generally, the promotion of the adolescent's own development was perceived through such activities as spending time with their peers, involvement with sports and school activities and enjoying leisure time when alone.

Acceptability by others was considered by some adolescents as the underlying reason for pursuing health and developmental practices. These adolescents indicated that they were involved in specific activities such as exercise and taking care of one's appearance (dressing appropriately, keeping hair neat, dieting) to improve one's image both for themselves and for others. As one older teenager stated, "I don't want to go around looking like a geek and have everybody looking at you".

Each of the adolescents interviewed described experiences involving learned physical skills in a variety of recreational, social or family situations. The majority of these experiences were related to sporting activities at school. Many were involved in team sports or in groups involving cooperation as well as competition.

As individuals, four of the adolescents indicated that they were currently learning new skills including soccer, tennis, swimming and driving an automobile.

None of these activities were shared with the physically disabled sibling, yet all were shared with peers. Only one adolescent shared a learned physical skill with her sibling and this involved a complementary type of sharing, music, versus competition. Two other adolescents stated that they played video games with their siblings, an activity that requires fine motor skill, one of whom indicated that the sibling was better at this "because he has more time to practice."

Task 2: Achieving a satisfying and socially accepted masculine or feminine role.

Each of the adolescents interviewed described appropriate masculine or feminine roles for themselves. Learning what it means to be masculine or feminine in today's society was achieved through observation of others, identifying sex-role expectations and practices that are accepted by society and incorporating certain behaviors into their own lifestyles. While all of the adolescents appeared comfortable in describing their current activities which reflected their status as a male or female, few shared their anticipation of what was realistically involved in becoming a man or woman.

All of the adolescents defined masculinity or femininity in terms of behaviors or activities, none being able to verbalize a theoretical definition. There was marked consistency in the descriptions of both male and female oriented activities provided by the participants. Female oriented activities primarily included shopping, trying on clothes, talking on the phone, gossiping, and spending time on one's appearance.

The following comments validate this:

"Girls like to go shopping, talk on the phone, just fool around with their hair and clothes and makeup"

"Being feminine means wearing makeup ...we talk about everything that comes in our mind"

"I like to fool around with my hair....I definitely like long hair best, because short hair makes me look like a boy"

"Girls gossip and talk about the fellows"

"I curl my hair to look like a girl...I can never get it to go right."

Two female participants indicated that they enjoyed activities which were considered by others to be male oriented and therefore inappropriate for girls. One girl stated that she had "given up wrestling because of what everybody would think about me, even though it's good exercise". Another female stated that she would like to have the opportunity to play ice hockey but felt that the

coaches were:

... prejudiced. If I could skate well enough I'd go down and try out for it anyway, because it would be discrimination if they said that I couldn't skate well enough.

Masculine oriented activities were consistently described by the male participants. These activities primarily included group sports and outside activities. "Guys like to play baseball and ride around getting into trouble". Male adolescents are also concerned with their appearance - "fellows try to look more mature and male by their posture", "I try to shave this peach fuzz to make it grow faster". One younger male adolescent was perceptive in attributing masculinity to self image. He stated that:

guys like to play pool or go bowling ...guys are interested in their looks because the way you look and your personality , well that's the way people look at you ...you have to keep up with the way other people act.

While traditional masculine and feminine traits were being expressed, a more liberal non-sexist attitude did prevail. While adolescents strive to develop their masculinity or femininity, especially in terms of appearance, a philosophy which allows for shared activities as well as individuality was demonstrated. All of the older adolescents and most of the younger

adolescentr, both male and female, stated that they had friends of both sexes and the primary activity of this group was "hanging out". The majority of the participants felt that it was acceptable to have both male and female friends and that either sex could be involved in whatever activities that were desired. As one stated:

boys and girls do not need to act differently from one another... they can do the same things, like hang around with each other.

Another older female stated that "women are equal, they can do what they want to."

Two of the participants acknowledged that there were some differences between being masculine or feminine. One female simply said that "men may be a bit stronger" and another was more direct when she stated that "...guys don't have to wear dresses . Guys don't have to worry about tampons or anything else like that."

Seven out of the 11 participants indicated that they had given little, if any, consideration to future anticipation of what is involved in becoming a man or a woman. Future considerations for themselves were primarily focussed on education and careers not on one's continued developing masculinity or femininity. Of the others, none had given consideration to the responsibilities involved with masculinity or femininity issues. One adolescent thought t'at the bcst things about becoming an adult

included being of legal age, getting more mature, marriage and having children. One girl who had not given much consideration to the future, had carefully considered the present when she stated, "I don't think that I want to be with anybody right now. I don't think I'm ready for it actually."

Task 3: Developing more mature relationships with one's age mates.

All of the participants perceived themselves as being members of at least one group of peers; many actually belonged to more than one particular group. While the majority of the adolescents indicated that they had friends of both sexes, few had developed closer personal relationships with a member of the opposite sex. The adolescents discussed the topic of dating in general terms, but did not provide in-depth data regarding experience in loving with or without premarital sexual involvement. However, a wealth of data regarding the adolescents' experiences with their peers was obtained.

Each of the adolescents interviewed freely described the activities of the groups in which they held membership. Membership in these groups can be classified in two ways: informal groups and formal groups. The informal group is usually a group of peers (who met through school or from the neighborhood) who "hang around"

together. The size of the groups described by the adolescents ranged from two to 11 with the majority of the groups having more than four members. This group usually includes the adolescent's best friend and is generally comprised of the same sex friends.

The activities of these informal groups is usually unstructured and occasionally specific activities are planned. As one 13 year old explained, "I hang around with my friends, there can be as many as 11 of us. We go for walks, go to the mall or to the snack bar, it doesn't really matter." Another, older adolescent stated that she "hangs around with a big bunch, there's usually eight of us...we walk around or go to the restaurant." This girl indicated that these friends are also involved in other groups or in different activities which do not involve the same friends. The male participants also indicated membership in groups of friends and the group activities centered around "hanging around" or playing sports.

Many of the adolescents were also members of more formalized groups. These groups usually originated from school based activities such as sports or committees. Six out of the seven females and one of the four males interviewed were involved in such groups. The girls were involved in team sports, volunteer groups, choirs or the school graduation committee. The one male who belonged to a formal group was a member of the school's hockey team.

Two of the other male participants indicated that they planned to join school groups in the next year when more opportunities would be available to them.

The physically disabled sibling of these adolescents were rarely involved in any of these groups.

One teenager stated that her younger sibling "occasionally" went with the group for a walk but this was usually when the adolescent was responsible for babysitting her. However, this girl also revealed that one of her friend's younger sibling was a regular member of the group demonstrating that it was not unusual for a younger sibling to be part of the group. Another teenager indicated that her sister with spina bifida was part of the group only during lunch at school. This was primarily related to the adolescent's responsibility to her sibling being rewarded with the "privilege of eating lunch with my friends in the classroom."

Few of the adolescents were involved in any of the groups to which their physically disabled siblings belonged. Three of the adolescents were aware of the teen group at the local rehabilitation centre but only one had ever attended a meeting with her sibling. The other two adolescents, whose siblings were younger, had attended the rehabilitation centre for other social functions with their siblings.

All of the adolescents had experiences in making and

keeping friends. Several different classifications of friends exist. Each of the adolescents had a best friend who was of the same sex. For the majority of the adolescents this best friend has remained a constant over the years. However, four of the adolescents indicated that they "had to make new friends" when the family moved from one community to another. Other types of friends identified were close friends who were the members of the informal groups, seasonal friends and relatives who were visited on holidays and boyfriends or girlfriends.

The adolescents did not describe much variance in the ages of their friends. The maximum age range among their friends did not exceed five years. Friends were generally met through school or in the local neighborhood. Occasionally friends were met through other groups, relatives or during vacations and camps. The adolescents described minimal social experiences with children of other ages, including siblings and their friends.

None of the adolescents stated that they had any difficulty in making friends but two described how they chose not to be friends with specific individuals because of remarks they had made about their sibling with spina bifida. In referring to the loss of this particular friendship, one girl stated:

We used to be friends but we're not any more, she makes fun of the way (sibling) walks and I don't like

it so I won't be friends with her any more.

However, when making new friends, the adolescents were often asked about their sibling, but as one individual stated "that doesn't bother me, I just tell them what I know." Another explained that he didn't have to explain it to his new friends because his "mother and his friend's mother were friends and the friend would already know about it."

All of the participants indicated that they were comfortable in social situations involving both male and female peers. The adolescents also reported a wide range of feelings regarding dating. There was a distinction made between dating and being friends with a member of the opposite sex. Dating is a more complex phenomenon with a preconceived notion of the expected behaviour of those involved. Six of the seven females interviewed acknowledged that they had experienced dating on one or more occasions in the past. For the younger adolescent, a typical date was initiated from a casual, spontaneous meeting or was arranged through mutual friends. Older teenagers tended to describe a more formal one-to-one relationship as their dating behaviour.

Dating was identified as one of the benefits of becoming a teenage for many of the participants, although one of the younger teens stated, "I'm not going to wait until I'm older" contrary to the parents' wishes. Dating

was considered a social event that was not impeded by having a physically disabled brother or sister. Some of the adolescents said that they had been asked by their dates about the sibling but the adolescent did not perceive this as influencing the dating process for themselves.

Only one of the adolescents interviewed perceived experiences that she called "true love" with a member of the opposite sex. All of the others described their relationships as "crushes" which were perceived as not permanent or future oriented. No information pertaining to intimate sexual relationships was related to the investigator.

All of the adolescents verbalized experiences which demonstrated their social skills involving friends. These experiences involved making decisions regarding activities, inviting and refusing invitations, solving problems and evaluating experiences with their friends. The overall peer relationship appeared to be based upon trust and loyalty. All of the adolescents demonstrated loyalty to their friends when asked to make decisions regarding invitations to parties or other social functions:

"If I couldn't ask all of my friends I'd have trouble choosing. I'd have to ask mom to change her mind."

"I'd invite them all or I'd invite nobody."

"I'd ask the first friends I saw, and hope the rest wouldn't hear about it because it would hurt their feelings....I probably wouldn't do it anyway."

In return, these adolescents trusted that their friends would return that loyalty if the need arose. One male adolescent stated that his friends were waiting for him to finish the interview so that he could join them swimming. The majority of the adolescents felt that their friends would not attend social functions to which the friend but not the adolescent had been invited.

The adolescents did not include their siblings when identifying friends, but occasionally included their siblings in activities involving their friends. All of the adolescents thought that their friends were aware that their sibling had spina bifida but did not think that their friends thought of the adolescent as being any different because of it. While none of the adolescents reported any difficulty in making and keeping desired friends, having a sibling with a physical disability does have some impact on the peer relationship and this will be discussed in-depth in the succeeding chapter.

Task 4: Achieving emotional independence from parents and other adults.

The desire to be emotionally independent from the parents was universally expressed by the participants.

There was some variance in the current degree of parental involvement in decision making particularly between the older and younger groups of adolescents and their parents. Many of the adolescents were able to acknowledge parental personality traits and were learning to predict parental responses to particular requests.

The issue of outgrowing parental dependence was a source of conflict between some of the adolescents and their parents. All of the adolescents are dependent upon their parents to provide basic food and shelter, yet may resent some of the parental expectations in return for this. The majority of the adolescents are still dependent upon the parents to provide other material things such as transportation, clothes and money. It was the latter two items that initiated the most conflict.

A few of the younger adolescents were the recipients of regular, set allowances which may be used to purchase lunch at school or other personal items chosen by the adolescent. Others received money in return for fulfillment of specific family responsibilities such as assisting with household chores or babysitting. Some of the adolescents supplemented this with money earned from outside sources. This money was generally spent in a manner chosen by the adolescent, usually on clothes or social activities. Others were given money by the parents to purchase specific items when requested by the

adolescent.

While general satisfaction was expressed regarding the origin of the money, conflict did occasionally arise regarding the adolescent's decisions regarding spending the money particularly if it was spent on clothes. One of the younger females admitted that she liked it when her mother approved of her selections because she (her mother) had good taste. It is interesting to note that this participant's sibling was close in age but was not asked her opinion regarding the purchase of clothes.

A few of the adolescents acknowledged that the parents should be involved in major decision making such as the selection of school courses and participation in activities that required financial support from the parents. Many of the adolescents indicated that the parents had made limitations regarding curfews and specific activities but the adolescents were in agreement with this. Few of the adolescents described experiences in which they were involved in making family related decisions. One girl said, "my father makes the decision about where we're going and things like that." With regard to family activities, the adolescents were often given a choice about whether or not they wanted to go but frequently they preferred to plan activities with their peers. Two of the adolescents were given choices regarding the allocation of bedroom space in the house, that is

which room they wanted, or with whom they preferred to share.

Many of the adolescents clearly defined the areas in which they were or would like to be responsible for making independent decisions. The primary area for independent decision-making was that of personal appearance. The adolescents decided for themselves what clothes to wear, what hairstyles they preferred, when to have a haircut and other appearance related decisions.

The adolescents also indicated that they frequently made independent decisions regarding social activities and the amount of time to be spent on homework as compared to extracurricular activities. Each of the adolescents stated that the parents had left the decision to participate in this particular study up to the individual. The parents had told the adolescent about the study and each had been asked if they wanted to participate. As one male stated "Mom said it was up to me and I didn't mind."

Of high priority in the decision-making area was the selection of friends. All of the adolescents indicated that they selected their own friends and made independent decisions regarding who their friends were. The majority of the adolescents were confident that their parents approved of their friends. In a few instances, the parents had advised the adolescent regarding the undesirability of certain friends and this had been met with mixed

reactions. One adolescent stated that she realized that her mother was right and another felt that the parents "couldn't say anything if we're not getting into trouble, I don't really listen to them."

Most of the adolescents described satisfactory relationships with their parents and other adults such as teachers. These adolescents generally described their relationship with their parents as "pretty good". One older girl described a particularly strong relationship with her mother by stating, "she's pretty good, I mean she's not too strict or anything. We can talk about anything." The adolescents did not perceive their relationship with their parents as being any different than the relationship between their siblings and their parents or as being any different than that of their friends and their parents. The following comments reflect the adolescents understanding of the parental relationship:

"Parents are all alike when you're growing up. They just want to protect you."

"Parents have to make some decisions because they don't want to see you get into trouble."

"I mean, every teenager has their squabbles with their parents ...mothers and fathers see what's best for you but we don't understand that."

The adolescents described their parents as

individuals in a variety of ways. Most of the parents were described in terms of their parenting skills as perceived by the adolescent. The parents were described as being reasonable and fair. Only one younger adolescent felt that the parents showed favoritism towards the younger sibling with the physical disability in that the adolescent said that she was "always the one who gets the blame." They say "you're older, you should know the difference."

The adolescents felt that they were generally able to predict how the parents would respond to various requests or behaviors. When describing a particular incident, one participant dramatically stated that "mom would kill me if she found out about it." Others gave evidence that they were able to predict the parents responses to other behaviors as well. "They'd never let me out of the house wearing a miniskirt" and "Mom would only let me have a small group in because we'd make too much noise" are examples of this.

In the process of becoming teenagers, the participants had noted changes in their relationships with adults as well as changes in the adults' expectations of them. The most commonly cited change was the parental expectation for increased responsibility as described by one adolescent:

Everyone expects too much from you, you have to behave in a more mature, responsible way. They say

you shouldn't be doing this, you're 15 years old and you should be able to do this or you're too old for that.

Most of the other adolescents described more concrete examples of increased responsibility especially household chores such as keeping their room tidy, laundry and other specified tasks.

Task 5: Getting an education for present and future roles in life.

All of the adolescents were enrolled in high school and the majority had made at least preliminary plans for the future. The adolescents expressed their ideas regarding sex-role stereotypes in relation to occupations. Many of the adolescents were currently involved in activities which involved the assumption of personal responsibility.

The adolescents demonstrated that they were acquiring the basic knowledge and skills for today's world through both the school system and their everyday experiences. All but two of the adolescents were in age appropriate grades in school, ranging from grade 7 to grade 12. Of those who described themselves as a year behind, one explained that he had a reading problem at an earlier age which was now resolved. The other explained that a family move had affected her placement in the school system.

Only one of the adolescents has had the experience of being in the same homeroom at school as the physically disabled sibling. This was a result of the sibling's hospitalizations and subsequent loss of a grade in school. Several other adolescents indicated that they were in the same school as their siblings and this did have implications for them.

The majority of the adolescents indicated that they were doing well in school and were proud of their academic accomplishments. Others admitted that they could "do better" particularly if they studied harder. The value of education was espoused by one younger adolescent who stated:

Schooling is important because if you don't finish school you hardly got a chance of getting a good job. I doubt if you'll get a good salary.

Other ways of acquiring basic ideas and skills for today's world primarily included observation of others, and participation in other events or activities. The adolescents identified parents and teachers as role models of behaviour and learning. One teenager had observed the teachers using a lift for her sibling at school and felt that, if allowed, she would be able to perform this procedure. An older adolescent stated that her ideas about family life and her expectations for the future were based upon what she observed in her own home. None of the

adolescents identified older siblings, whether disabled or not, as role models.

Knowledge and skills were also learned through involvement in activities such as craft making, organized team sports, informal group activities and individual lessons for driving and sports. All of the older adolescents and some of the younger ones were also learning skills through the acquisition of jobs such as babysitting or part-time jobs within the community.

While none of the adolescents had received any formalized training for holding a job at the current time, several were taking lessons or were involved in activities that were preparing them for this eventuality. The older adolescents stated that the primary reason for seeking employment was to earn personal spending money. As one stated, "It's my money, I earned it so I can do what I want with it."

Considering the age range of the sample, few were of legal age to obtain employment positions, therefore the assumption of personal responsibility was considered in terms of the adolescents' reactions to group membership or family responsibilities or other assumed responsibilities such as babysitting. All of those involved in more than one team sport or activity demonstrated maturity in their decisions regarding the attendance at practices or games. Commitment to the group as well as to the activity was

evident. Several explained that the team was "dependent on you" or that "you wouldn't want to let the team down by not showing up without a good reason." One participant particularly described her commitment in her statement that she was "not a quitter." Others described their commitment to holding babysitting jobs (outside the family) or other paying positions. They described themselves as reliable and trustworthy when holding these positions.

The majority of the adolescents had given consideration to the types of careers they would like to obtain upon finishing school. The younger males were the least specific about their career plans. Two out of three admitted that they actually had not given this much consideration as of the present time and one of these then stated that he thought he might like to be involved in the same business as his father. One younger male participant had considered joining the militia, but did not differentiate which aspect of the militia would interest him or how this could evolve into a career.

All of the females and the older male interviewed verbalized the types of careers they were potentially interested in, thus indicating that they had given this previous consideration. They were also able to identify the need for academic achievement and attendance at appropriate secondary schools to fulfill their goals.

Six out of the seven females identified helping careers for themselves, and two of these related their career choices to the experiences of being the sibling of a physically disabled child. One girl wants to become a speech therapist because "I like to help children ...I'd like to learn sign language, I'd love to work with people. I think it (having a sibling with spina bifida) has made me more sensitive to the needs of children." Another girl who thought that she would "probably become a nurse or a teacher because I've always wanted to be one" also acknowledged that she watched what the nurses were doing when she visited her sibling in hospital. One girl who wanted to be a doctor had been hospitalized briefly herself and had visited her sibling frequently in hospital and was currently volunteering at a local hospital.

A broad range of potential careers or occupations were identified by the group, yet individual choices were consistent with the past and present social and academic experiences described by each adolescent. The career options considered included neonatologist, speech therapist, child psychologist, veterinarian, day care worker, nurse, teacher, lawyer, sports journalist, food technologist, electrician or carpenter.

With respect to one's sex-role attitude towards future work and family roles, the adolescents did not attribute specific roles to either males or females. None

of the younger adolescents had considered sex-role attitudes in relation to career choices, but neither had they fully considered any career for themselves. All of the older adolescents did not consider the majority of occupations as being either male or female oriented. They felt that "men and women can do whatever they want." Two participants felt that there could be an exception to this if the job required physical strength.

Task 6: Preparing for marriage and family life.

The older adolescents were more involved in the process of preparing for marriage and family life than were the younger adolescents and this was reflected in the experiences and perceptions described by the adolescents. There was a distinct difference in the responses between the younger and older groups but the difference was less distinguishable between the male and female groups. All of the adolescents made references to their sibling with spina bifida when discussing issues related to family living, family roles, marriage or raising a family of their own.

The formulation of sex-role attitudes involved in marriage and family living often reflected the situation that the adolescent observed in their own home with both traditional and modern viewpoints expressed. The older adolescents stated that male and female roles were equal

in the family and felt that mothers and fathers should share household tasks and child care. Two of these adolescents added qualifiers. One stated that the roles assumed in the house should be equal but depended upon who was working outside the home: "I mean, if the mother or father is working, then the other one should take care of the house and do the cleaning. It's not fair for one to have to do it all." Another older adolescent explained that a mother's and father's role in the house are "much the same really, they're a lot the same" in terms of responsibility and teaching a child right from wrong, yet perceived a uniqueness in each parents relationship with the child "a father has a father role and the mother can't take that away from the father, but the father should do as much now as the mother, clean the dishes, cook supper." This individual stated that this viewpoint did reflect what was observed within her own home.

Three younger adolescents, two males and one female, did not verbalize any statement reflective of developing sex-role attitudes involved in marriage and family living. One female who was the oldest child in the home did perceive parental roles as being equal and had observed a sharing of household tasks between her parents. Two younger males possessed more traditional viewpoints in relation to specified male and female roles within the home. One of these felt that he actually had less

responsibility in the home because he was male and did not expect this to change in the future.

When describing the responsibilities as well as the privileges of family membership, each of the adolescents made references to their sibling with spina bifida. The responsibilities that the adolescent is given or assumes for the sibling are significant in terms of their influences, not only at home, but in school and with their friends. These influences will be presented and discussed in further detail in the next chapter. Some of the adolescents also perceived that they had more responsibilities, not just for the sibling but because of the sibling. One girl felt that she had more responsibility at home than her sibling because she was female, younger, and because her sibling wasn't able to "help that much around the house", but did not express any resentment about this.

The adolescents also described other responsibilities and privileges within the family that were not specifically related to having a sibling with spina bifida. The major responsibility that the adolescent had to assume was an increase in parental expectations related to both household chores and to mature decision-making regarding social activities. Frequently this was rewarded with increased privileges for the individual such as a later curfew or more money to spend. Some of the

adolescents did identify privileges in belonging to their particular family, but this was related to the perception that their parents were "fair" or "less strict" than the parents of their friends. One girl stated "I couldn't ask for better parents. I'd say I was pretty lucky to get here."

Another adolescent perceived both positive and negative aspects in belonging to a larger family:

We're very supporting of each other and we can help each other and we get along great...(but) well, you don't always get your own way.

The adolescents were in the process of developing attitudes towards marriage and raising a family. For some, this process included the identification of tasks involved, particularly in maintaining a household and childrearing. For others, this process involved serious consideration of the perception of risk of having a disabled child of one's own. The attitudes that were expressed were often reflective of what was observed in their own home or based on personal opinion.

Eight of the eleven participants had considered marriage in the future and marriage was closely associated with having children for most of them. One girl stated:

I'll probably be married but I'll never have children...because I don't want to have children. I'll probably adopt. I've always said that I'd love

to raise a child but I don't want to get pregnant. She did not specify if this was related to fear of having a child with a physical disability such as spina bifida, but said that she had never discussed that possibility with anyone.

Another participant who openly said that she did not intend to get married commented that she thought about her disabled sibling and described a strong family history of "something being wrong with the back, so it's a good possibility" that she could have a child with a similar problem. Again, this girl had not discussed her concerns with anyone.

One participant felt that he would have to get married because he wanted a son. He also expressed strong feelings towards the possibility of having a child with spina bifida when he stated, "I think I'd die then if I had one of them, I'd die."

Only one adolescent, who was currently involved in a serious relationship, acknowledged that she had discussed the possibility of having a child with a disability with her boyfriend. This girl emphasized the positive aspect of such a possibility by perceiving a closer relationship with the child because of the responsibility it entailed.

The concept of love was closely associated with marriage. Love was identified as a criterion for marriage or a relationship which involved a commitment. While one

younger adolescent admitted that she "loves all boys", most of the others distinguished between various types of feelings for others. One older girl defined the difference between a "crush" and "being in love" as:

Well a crush is perfect. You just admire the person from afar and you don't have to be stuck on to him all the time and you don't have to follow him around everywhere and do what they tell you to or anything like that or go where they want to go or ...but being in love, well I don't know, I think it would be nice because you know then you'd have the person who you know, you'd be partners right, participate with the person and everything.

Only one of the adolescents interviewed was currently involved in a serious personal relationship with a member of the opposite sex. Others indicated that they had been involved in casual relationships in the past but most of these were not described as serious.

None of the adolescents had made specific commitments regarding the timing of engagement or marriage. For most, this was secondary to the completion of one's education. Many of the adolescents had demonstrated that they had made mature decisions regarding the multiple demands that are placed upon youth in today's society. They had opinions regarding teenage pregnancy, drinking and driving and other social issues.

Task 7: Developing the knowledge, skills, and sensitivities required for civic competence.

The experience of having a sibling with spina bifida provided many of the adolescents with opportunities to acquire a degree of civic competence. These experiences supplemented other experiences to demonstrate the adolescents' ability to communicate ideas to others, to become involved in causes outside of oneself, to effectively solve problems and to develop concepts relevant to the modern world.

All the adolescents were able to verbally communicate their ideas and experiences related to being an adolescent and to being the sibling of a physically disabled child. They also had at least one experience which involved communicating information to others about spina bifida. One of the older adolescents had volunteered to report on spina bifida to her classmates because "people don't know anything about it." The others had more informal experiences related to being asked by strangers or friends about their sibling. One younger girl felt that she would be able to adequately explain spina bifida, but also perceived that a few people asked her questions because they were "afraid to hurt (her) feelings."

In other aspects of communication, two of the older adolescents felt that they were good listeners and this trait had been identified by their peers. None of the

adolescents described any other experiences which demonstrated their ability to communicate their ideas or concerns to people other than their peers or parents.

Many of the adolescents were involved in causes which benefited others and displayed socially responsible behaviour. The primary source of involvement in causes outside of oneself was the physically disabled sibling. Those adolescents whose sibling was moderately to severely disabled were more likely to be involved in their care, either at home or in school. The majority of the adolescents also indicated that they became involved with their sibling when the need arose to defend the sibling to others. Many of these adolescents recalled vivid experiences and described in detail the circumstances surrounding such incidences.

A few of the adolescents described their involvement in other groups or activities which benefited people other than their siblings. One girl belonged to a volunteer group which helped senior citizens or provided entertainment to others. Another girl was involved in counselling others in an after school program and also participated on various school committees.

The adolescents also demonstrated responsibility in their social behaviour. This was reflected in their choice of friends and their decision to participate or not participate in various social activities. The social

activities in which the adolescents chose to participate were socially acceptable and generally approved of by the parents. Most of the adolescents were cognizant of the issues surrounding youth, such as drinking and driving, drug use, teenage pregnancy or AIDS. Some of the older adolescents strongly stated their objection to drinking and driving even though this behaviour had been witnessed in their peers. One adolescent explained her intervention in a situation involving a friend who was planning on driving while under the influence of alcohol:

I think it was better for him to get into trouble (because the girl had telephoned his father) and to be mad at me, than for him to take his own life into his hands ...or to hurt an innocent bystander.

Other adolescents suggested taking the driver's keys, calling a taxi or calling the parents to prevent drinking and driving.

The female adolescents also demonstrated a mature attitude toward the issue of teenage pregnancy. Some of these adolescents had witnessed their friends' pregnancies or were aware of other girls who had become pregnant. The most consistent response to this situation was the consideration by the adolescents that this need not have occurred given that birth control was available.

The adolescents had acquired individual problem solving methods for dealing with modern problems. The

methods used varied from asking the peer's opinions before making a decision, observing the friend's behaviour, telling "little white lies", or relying on one's own judgement. Rarely were the parents consulted when the adolescent was faced with a problem related to their peers. Neither did the adolescents state that they used family responsibilities as an excuse to avoid undesirable social situations.

Of the concepts relevant to the modern world that were discussed during the interviews, the adolescents primarily described experiences related to economics and human nature. The concept of economics was perceived from an egocentric point of view in that the adolescents were mostly concerned with means of obtaining and personally disposing of money. Increased independence was associated with the acquisition of personally earned money and the majority did feel some responsibility towards earning money for their personal use. The relationship between money and value was not discussed nor was economics in the broader context of society addressed. One adolescent felt that his family had more material belongings than the families of his friends and another felt that her parents had spent a great deal of money in providing registration and equipment necessary for her to maintain her sport and hobby and that she would like to either repay her parents or assume this financial obligation for herself.

The adolescents expressed various opinions regarding human nature which was described as the "way people are or the way people act." These opinions were based on the everyday experiences of adolescence as well as on specific experiences related to being the sibling of a child with a physical disability.

One older adolescent, who described satisfactory personal relationships with most adults, perceived that adults had a negative opinion of teenagers in general when she stated:

Adults consider all teenagers, you know, you should stay away from them, they're evil, they're rowdy, and they don't speak civil to you or anything and they're always getting ahead of you in the line at the store and the salesladies in the store are always looking at you to make sure that you don't take anything.

The adolescents described various aspects of human nature, including the way their peers reacted to different situations, and their parents' responses to specific adolescent behavior. The adolescents often expressed their own ideas as to why people behaved in the way they did and this was unique to each adolescent.

There was some consistency in the way many of the adolescents perceived others' reactions and responses to their disabled sibling. The witnessing of others' reactions to their sibling afforded the adolescent with

the opportunity to examine human nature. One girl felt that people automatically "pity" a person in a wheelchair, especially if that person was a child and tend to treat that person differently. Another adolescent felt that adults were often less understanding of a child's disability than other children.

One of the adolescents had observed more positive human responses to the disabled sibling:

Most of the people around here are used to disabled people because we have a TMH (trainable mentally handicapped) class in the school. I find that most of the fellows are really nice because this was (Sibling)'s first year in our school and all the grade 12 befriended him and everything and they were really nice to him and one guy even used to drive him back and forth to dances. They're really nice.

The adolescents were all in various stages of the process of developing the knowledge, skills and sensitivities required for civic competence. The older adolescents had a greater variety of experiences and thus were able to demonstrate increased development in this area. The experience of having a sibling with spina bifida impacted upon the adolescent in terms of their development as a socially responsible person and in the development of personal concepts related to human nature. These areas will be discussed in further depth in the next chapter.

Task 8: Establishing one's identity as a socially responsible person.

The data which supports the adolescents' development of an identity as a socially responsible person frequently overlapped with data which has supported other developmental tasks. The process of attaining values and ethical controls influences both the implementation of worthy ideals and a workable philosophy of life. This process is reflected in the involvement in causes which benefit others and the assumption of social responsibilities both in the home and in the community as was previously discussed in earlier tasks.

In assessing the adolescents' development of a workable philosophy of life, their general beliefs were examined. During the adolescent years, there often exists confusion regarding the self and its fit with society. The adolescents who were interviewed for this study exemplified some of this confusion but generally held a positive outlook towards life and maintained that values of honesty, integrity, and individuality were vital to the development of the self as a worthy person. One girl explained the benefits of becoming a teenager: "you're getting older and growing up and able to do more ...you've got to act like yourself." Another girl revealed that it was important to her "to be myself and, you know, to act myself and to try to help out when needed."

The importance of doing well in school was perceived by one adolescent as beneficial for the self:

We (referring to herself and her sibling) do things for ourselves and not for others. When we were younger we used to get like you'll get this if you pass or that if you pass but now it's not so much because we are doing it more for ourselves than anybody else.

The establishment of one's identity as a socially responsible person during adolescence incorporates the perceptions of oneself. The adolescents in this study characterized themselves using a variety of terms. Individually, they described themselves as "soft hearted", having "more tolerance", being "fairly patient" or "unselfish" in response to questions regarding the influence of having a physically disabled sibling on their personality. The adolescents acknowledged that these descriptors had been used by parents and peers as well and thus provided a source of positive reinforcement for the adolescent.

Other unique personal characteristics were applied individually by different adolescents. Some described themselves as shy whereas others were more extroverted. Most of the adolescents were cautious in nature but a few considered themselves to be more adventurous. One of the male adolescents actually described himself as "paranoid"

and further explained that "I always think that people are looking at me, I get embarrassed easy [sic]." This individual indicated that he preferred to be with "the crowd" rather than going places by himself. Other terms used by the adolescents to describe themselves includes generous, outgoing, talkative, and easy to get along with. Younger adolescents tended to describe more appearance characteristics when describing themselves, i.e. short, skinny, good at sports, whereas older adolescents tended to describe more personality traits.

The adolescents demonstrated a maturity in the implementation of worthy ideals and standards in their lives. As a group, there was consensus regarding the social issues facing youth in today's society as was previously discussed. Yet, a degree of idealism surfaced, particularly with the younger adolescents, who perceived themselves as invincible against some of the issues. For example, the younger female adolescents who had witnessed their peers' teenage pregnancies, held an attitude that this couldn't possibly happen to them. Again, there were some differences in the attitudes expressed by the older and younger adolescents. The younger adolescents were less likely to espouse theoretical beliefs and most of their values and ideals were materialistic and/or egocentric and tangible in nature.

The adolescents wanted the friendship of their peers

and the respect of their parents and other adults. To accomplish this, they were honest and reliable with minor deviations that were not perceived as causing harm to others. For example, one participant who described herself as a good friend to others and felt that she had a solid relationship with certain adults admitted to occasionally withholding information about herself or others. For some, the worthiness of some friendships was questioned. One girl explicitly stated that she chose not to befriend a person because of remarks made about her sister. Another male stated that people who tried to coerce an individual into "doing something that you didn't want to do wasn't a real friend anyway."

The implementation of ideals and standards in the lives of these adolescents included their development of a positive attitude towards individuals with a disability. One common theme which emerged from the data was the belief that the sibling with spina bifida was not "different" from any other individual and that the adolescent was not different because he/she had a sibling with spina bifida. This belief that the sibling with spina bifida was not different was frequently qualified with a statement that began with "but....." and certain differences were identified. The fact that differences were actually identified has an impact upon the development of the sibling and this will be discussed in

the next chapter.

All the adolescents recognized the value of the family and included parents and siblings in the list of the most important people in their lives. Of equal or lesser importance to the adolescents were friends with the possible exception of the best friend who was sometimes rated as of greater importance than the sibling or the parents. One adolescent who stated that the family and friends were very important to her further explained:

It's not so much that, but the relationship that we have, (friends) are somebody that you can talk to, that you couldn't tell things to your parents that you tell to your friends and vice versa and the relationship of trust that you have with them.

The analysis of the data revealed that the adolescents are in the process of achieving the developmental tasks appropriate for their age group. All of the adolescents were able to communicate experiences which demonstrated their developmental status. As would be expected there are significant differences in the degree to which younger adolescents are currently achieving these tasks as compared to the older adolescents.

The adolescents generally described positive relationships with their families and with their sibling with spina bifida. However, the experience of living with a child with a physical disability did have some impact on

specific developmental tasks and thus on general areas of life which influence the developmental process.

CHAPTER 5

Discussion

The Influence of Living with a Sibling with Spina Bifida on the Psychosocial Development of the Adolescent

The intensive analysis of the data revealed that having a disabled sibling does influence the achievement of various tasks of adolescence. The experiences gained through living with a brother or sister with spina bifida provided many adolescents with the opportunity to demonstrate their maturity in various aspects of development. The adolescents also described a multitude of experiences related to their sibling which indirectly affected their development but were not coded or categorized in terms of the developmental tasks. References were made to the development of the sibling with spina bifida, the relationship between the siblings and the impact of this relationship on the adolescent's own development.

An examination of the data related to each of the categories corresponding to the eight developmental tasks, and the data that did not specifically fit the developmental tasks that were coded separately, indicated that having a sibling with a physical disability such as spina bifida has an impact upon six major areas during adolescence. These areas are: 1)family responsibilities, 2)parental relationships, 3)sibling interaction, 4)school,

5)peers and 6)personal maturation. Although the data supporting this conclusion is presented individually for each aspect, along with a discussion of pertinent literature, there is much interaction and overlap between the areas. That is, what influences the family responsibilities may also have an impact upon school experiences in a similar or in a different manner and so on between the six areas.

Family responsibilities

Many of the adolescents related a difference in their involvement in family or household related responsibilities to the presence of the sibling with a physical disability. However, for the majority of the adolescents this difference was not perceived as having a negative impact but neither was it overwhelmingly perceived as having a positive impact. Generally, the increased responsibility was accepted as an increased expectation of themselves as a result of becoming a teenager.

Several of the adolescents identified increased responsibilities in the care of their siblings (both siblings with spina bifida and younger, non-disabled siblings). Adolescents who were older than their sibling with spina bifida or of the same sex indicated a greater degree of involvement in the direct care provided to the

disabled sibling. Caretaking primarily involved babysitting in the absence of the parents which was in itself not considered to be a responsibility that was any different than the responsibilities assumed by their peers. However, the responsibilities inherent in the babysitting task, such as diapering, observing for seizures, providing appropriate entertainment, and assisting with meals were considered different. One girl expressed mixed emotions regarding her babysitting responsibilities; she admitted to "finding it hard because I have to do everything" but qualified this by stating that she would "do anything for (Sibling) because I'm the only one here. I mean, he can't get it himself."

The adolescents also indicated that they assumed other caretaking responsibilities at home for their sibling including bathing and dressing the sibling for school, procuring unattainable items from high cupboards and assisting them with physical activities. None of the adolescents indicated that any of these responsibilities were voluntarily assumed by themselves or specifically demanded by the parents.

Many of the adolescents stated that they were expected to increase their responsibilities in terms of household chores as a result of becoming a teenager and/or because their sibling was less physically able to assist in this area. Thus, maturation and the presence of a

disabled sibling had an interactive effect in the developmental area of increased responsibilities. Only one adolescent, a younger male, did not anticipate that he would be expected to assume more household chores. This same adolescent reported that his father did not regularly participate in household duties and this may account for the adolescent's expectations.

Meanwhile, the adolescents also expressed an opinion that their siblings were often capable of doing more for themselves and assuming more household responsibilities than they actually did. One adolescent described how her sister could perform such tasks as making her own bed "if she felt like it but she's too lazy." The adolescent was required to make her sister's bed. The adolescent commented that she didn't like to do things for her sister that the sister was capable of doing for herself but didn't mind helping her with activities that were beyond the sibling's physical abilities. Comments such as the one cited above reflect the adolescent's mixed feelings regarding his/her sibling's disability. The adolescents often consider their siblings as being "normal", yet simultaneously acknowledge that there are differences. The findings support those of Seligman (1987) who suggested that children with chronic illness may demand a great deal of attention from their siblings. As a potentially negative consequence, Seligman also states

that "children may be pressed into parental roles they are ill prepared to assume and may move too rapidly through the developmental stages so necessary for normal growth" (p. 1250).

Simeonsson and McHale (1981) also suggest that there may be a negative outcome to the increased physical demands made on siblings of disabled children. It was suggested that the sibling experiences resentment as parents expect more from the non-disabled child in addition to the reduced attention given to that same child as compared to the child with the disability.

In this study, the adolescents did not express any resentment towards either their disabled sibling or their parents for this increased responsibility. Also, the adolescents did not indicate that their sibling with spina bifida made excessive demands on them and those requests that were made were usually associated with babysitting.

For some adolescents, there was a change in family responsibilities related to the hospitalization of the child with spina bifida. The majority of the siblings recalled experiences related to their sibling's hospitalization and how they were affected by it. Hospitalization of the sibling resulted in increased responsibilities at home if the adolescent was expected to assume the sibling's or some of the parents' tasks related to maintaining the home. While the hospitalized sibling

was not considered ill but in need of surgery, the adolescents assumed personal responsibility for visiting them in hospital. This was a choice made by the adolescent which may have been encouraged by the parents. As one individual concluded:

You can't just leave (Sibling) there, (Sibling) gets so depressed and its hard on (Sibling) and its hard on the family, beating back and forth to the hospital all the time as well as having to do everything else.

For two adolescents, the time spent visiting the sibling was also considered to be important for the sibling but may also mean less time available to spend with their peers. None of the adolescents perceived any degree of parental neglect during their sibling's hospitalization but rather understood that this was a parental priority at that time. Those adolescents who had been hospitalized themselves for various reasons perceived no difference in the way the parents treated them as compared to the way the parents treated the siblings during their hospitalizations.

Parental relationships

The relationship between the adolescents and their parents was also influenced at times by the presence of a child with a physical disability in the home. Many of the adolescents felt that their parents treated all the

children in the home in basically the same manner. There were some perceived differences, particularly in relation to favoritism, due to the sibling's physical disability.

In one study of families with a chronically ill child and a well sibling, King (1981) was unable to validate that parents demonstrated "differences in attitudes towards child-rearing practices based on the presence or absence of chronic illness in the child" (p. 193). However, King rationalized that the degree of illness or disability may be a factor which influences the child-rearing practices employed by the parents.

Scheiber (1989) compared the interactions between parents and their developmentally delayed children with the interactions between parents and the normal preschoolage siblings. The findings of this study (comprised of a small sample of seven families) indicated that the families use a variety of ways to solve problems but that similar home environments were provided for both children within the same family.

One adolescent explained that although her parents tried to provide equally for the children, the one with spina bifida was usually the first one to receive desired items, especially those items associated with indoor entertainment. Although this opinion was rationalized in terms that the adolescent was "able to get out more, especially during the winter", it was not perceived as

fair treatment:

Sometimes I get mad. I don't think it's fair but it's what you've got to put up with. They (my parents) just laugh at me, they think I'm only joking, but sometimes I'm not.

Another girl expected that she would be treated differently, given that she was the only daughter but acknowledged that:

We're all treated equal, except (Sibling) who's treated a bit more better [sic] because he got what he wanted . Like he asks can I have this and it's sure (Sibling) can have this. Or if it's me and (Sibling) having a fight, who's fault is it, definitely not (Sibling)'s, it's mine.

In another family, the adolescent felt that:

Sometimes I think that mom likes (Sibling) better. If we're arguing, she'll (mother) hear (Sibling)'s side of the story and she won't hear mine Dad says "don't fight with (Sibling), that's a sin, right.

As a result, the adolescent felt that the younger sibling with spina bifida was "getting away with more".

However, most of the adolescents described their relationships with their parents as being comparable to the relationship between their peers and their parents.

Sibling interaction

The relationship between the adolescent and the sibling with spina bifida also influences the development of the adolescent. The adolescents described a variety of experiences representative of the relationship between the siblings. In describing these experiences and exploring their relevance to the development of the adolescent, the age and sex differences must be considered. The adolescents discussed activities they shared with the sibling and their feelings about their relationship with their sibling.

Several of the adolescents who were older than their sibling with spina bifida remember the birth and/or being told about the baby. One female adolescent recalls normal feelings of resentment towards the baby:

I remember my birthday was coming up. I remember the first time they laid him on the bed. I really hated him, I didn't know he had spina bifida or anything. I knew he had this thing on [splint] but besides that, it was like I used to be the youngest, now he's coming in, so it was like the first time mom laid him on the bed so I hauled his hair.

Another adolescent vividly remembered seeing her sibling for the first time :

The very first time I saw her was when dad took us down and he just explained what was wrong. The

nurse, we were looking in the room, in the glass window, and the nurse was holding her up and she was really cute but then she had something over her head, like you know, where the shunt was, so that was all we really saw of her, they wouldn't let us in to see her.

The adolescents who were old enough to remember the birth of the child with spina bifida had memories of their parents being very upset and crying. Several recalled trying to be very helpful especially when the baby first came home from hospital. The adolescents, who were younger and did not remember the birth of the baby, did not specifically recall asking the parents for any information but a few recalled when their parents explained that there was "something different" about their sibling. They did not remember this as being a traumatic event in their lives.

The adolescents generally referred to their siblings with affection. However, the amount of time they spent together and the types of activities that they shared were limited and varied with each sibling-dyad. Same sex siblings who were close in age tended to spend more time together in recreational activities, with the exception of one dyad in which the sibling with spina bifida had a severe disability. One sibling-dyad, which consisted of a male and a female adolescent who were close in age, shared

many interests and activities and the relationship was described as "great..for a brother and sister."

The majority of the interactions between the siblings as described by the adolescents were not reciprocal in nature. Frequently, the interactions were based on the need for caretaking or assistance or were one-sided in that the adolescent was doing something for the sibling. Many adolescents stated that they took their siblings "for a walk in their wheelchair" or accompanied them to the store or to activities designated for the sibling. Activities that were shared were limited by the physical disability of the sibling with the most common types of shared activities involving board games, computer games, watching movies, and craft making. Only one adolescent who was several years older than the sibling indicated that she enjoyed playing dolls and school with her sibling which were appropriate activities for the younger sibling. Other adolescents who did spend time with the younger siblings tended to share activities that were of interest to the adolescent.

The adolescents rarely included their sibling in peer group activities but this may be related to a multitude of factors. During adolescence, the focus of activities is often centered around peer group versus family centered activities. Also, the type of activities in which the adolescents were engaged involved major physical abilities

such as sports. Siblings who had minimal physical disabilities shared in some activities such as swimming, but none participated in more vigorous sports. Age and sex differences may also contribute to the minimal interaction between the siblings and their peers.

The adolescents believed that their siblings with spina bifida had many friends of their own and easily made friends. The adolescents who described their siblings as having many friends actually spent less time with their siblings. Perhaps, as the child with the physical disability is also developing and increasing his/her own social resources, the adolescent may be relieved of some responsibility for the sibling. Few of the adolescents suggested that the sibling's ability to make friends was related to the physical disability. These adolescents expressed concern that others would "take advantage" of their sibling or would "feel sorry" for them and thus try to be friends. This evoked feelings of protectiveness towards the sibling.

The adolescents were often concerned about other people's reactions to their sibling and responded to this in a variety of ways. One girl described her feelings about an incident at a local community event:

(Sibling) was just sitting there, and he's helpless. People just come up to him, one lady gave him a teddy bear. Other people shy away from him and haul their

kids away. Stuff like that really annoys me. People treat him differently because he's in a wheelchair. That's the way it feels to me.

Some of the adolescents were perceptive enough to notice that while they (the adolescent) may react to certain social responses, it did not always seem to affect the sibling themselves. The adolescents described how they needed to defend the sibling but the sibling did not appear to be upset about it. Most of the adolescents perceived their siblings as being capable of defending themselves should the need arise.

One of the most striking and consistent findings of this study was the revelation by the adolescents that they perceived their sibling as being "no different....but." The adolescents were emphatic in their statements that their sibling was not different from other children in the family, including themselves, nor did having a sibling who had some degree of physical disability imply that the adolescent was "different" from their peers. However, the adolescents did frequently add qualifiers to the basic statement that the sibling was not different. The differences became evident when the adolescents described some of their responsibilities at home and/or at school involving the sibling and the impact it has had on their social lives. Many of the adolescents also acknowledged that the sibling may actually be different but had

difficulty in verbalizing the difference.

One adolescent initially stated that there was no difference in having a sibling with a physical disability, but later acknowledged that she really did not know if there was a difference because she did not have a sibling without a disability. Another adolescent who stated that there was no difference in having a sibling with spina bifida "except that you have to watch out for them a little more" and also described the sibling as being a "little slow (physically) but (Sibling)'s okay." The difference in terms of physical ability was also identified by other adolescents.

Some adolescents tried to explain the difference between their sibling and other children:

They're [children with disabilities] special in the sense that they're not different from everybody else, like people say, well okay, that's a different kind of kid, but in a way that person is special because they're able to adapt.... They go and they live a normal life, right. So I mean I think that's special.

Another adolescent who stated that he did not perceive his sibling as being different, but thought that other people may consider the sibling as being different:

People may pick on (Sibling) because they think he's a bit different than anybody else. He might act different, he might walk a little bit strange and

stuff like that but he's really no different.

This same adolescent continued to explain that the sibling did not receive special attention from the family and that this was beneficial for the sibling:

He's treated just like everybody else. It's good, so he doesn't feel like he's different from everybody else or he's strange or something. That's how you should treat anybody with a disability. (Sibling) is pretty normal compared to what he's got because lots of people with spina bifida can't walk and they're in wheelchairs and everything. Some of them can't speak or learn.

Many of the adolescents also acknowledged that there were some differences in being the sibling of a physically disabled child in that the adolescents were able to offer advice to others who shared similar circumstances. In fact, much of the advice that was offered was related to the perceived difference or lack of difference in having a brother or sister with a disability caused by spina bifida:

I'd say, she [sibling with spina bifida] is no different than anybody else. You have to watch out for them a little bit more, but like they don't need any more, you don't have to treat them differently.

You have to be patient because they're different in a

way, but they're not. Like they need a little extra attention than I would. You just have to take it one day at a time.

It's really no difference, I mean I'd say, it's not much you can do. I mean just stick with it and help them go through it It's harder if they're really sick or always going in for operations. If that's their situation, I'd just say stick with it.

If they [other people] know somebody with spina bifida and they're shying away from them, I'd say don't go shying away any more and I'd say they [children with spina bifida] are just as good as anybody else.

I'd just say, care for them, be nice to them, help them, just do it for them because they can't get around or anything.

Love them as if there was nothing wrong with them. I would say treat them the same and I'd say there really isn't any difference. I mean how would you like to be treated if you had that problem. I mean they're special kids, they're great kids, you know.

I'd say, well boy, I suppose they're just as good as if they could walk and they're not going to come out at you. The worst thing about it is when you're in another room, they yell out to you all the time.

One adolescent's advice was to find out more about the condition and suggested that the person with a brother or sister with spina bifida "get some information, phone the rehab centre [Children's Rehabilitation Centre] or whatever and see what you can find."

The feelings of "differentness" experienced by the siblings in this study are similar to the results reported by Skrtic, Summers, Brotherton, and Turnbull (1984) on siblings of severely disabled children. These authors suggested that during adolescence "there may be a heightened awareness of the differentness of the handicapped sibling" (p. 239).

Sibling interactions were often described as one-sided with the adolescent "doing something for" the sibling with spina bifida. Siemon (1984) suggests that the quality of sibling interactions is influenced by an illness or disability in one of the children in that the "natural combat and conflict" (p. 300) experienced by siblings is suppressed by guilt and that the well child is unable to express his/her true emotions. However, Faux (1986) found that the frequency and type of sibling interactions between school-aged children was not

significantly altered when one child was congenitally impaired with either a craniofacial or cardiac anomaly.

The relationships between school-aged and adolescent children with autism or mental retardation and their siblings were studied by McHale, Sloan, and Simeonsson (1986). The findings of this study suggested that the quality of the sibling relationship was related more to specific problem areas such as perceptions of parental favoritism, coping ability, and concerns regarding the sibling's future than to age, sex, or family size. In the current study, some adolescents did perceive a degree of parental favoritism towards the child with the disability, but none of the adolescents suggested that this favoritism influenced the relationship between the siblings.

School

A great deal of adolescent time and activities are centered around the school environment. Thus, school is perceived as a contributing factor in the development of adolescents. Many of the adolescents in this study attended the same school as their sibling with spina bifida and related experiences during school hours which may have influenced their own development. The primary influence of these experiences on the development of the adolescent is related to the responsibilities of the

adolescents for their siblings during school. These are experiences which were not common to the adolescent population in general and thus not usually shared by the friends of the adolescents.

The adolescents in this study did not describe any experiences which indicated maladjustment problems at school, nor did they describe any activities that could be interpreted as behavior problems at school. This is different from the findings of Tew and Lawrence (1973) who reported that siblings of children with spina bifida were four times more likely to have maladjustment problems (confined to school problems) than siblings of a control group of subjects. The absence of maladjustment problems in school for the adolescents in this study may be a reflection of the acceptance of their siblings by themselves, their families and their friends.

Most of the adolescents indicated that they either attended the same school as their sibling and/or had some responsibility in assisting their sibling in preparation for school on a daily basis. Two adolescents who attended the same school as their sibling and stated that they did not assist their sibling in preparing for school were both male and their siblings were described as having minimal physical disabilities and could therefore manage on their own. One adolescent who had previously attended the same school as the sibling was responsible for ensuring that

the sibling was brought to the taxi each morning but now did not have that responsibility.

The female adolescents were more involved in assisting their siblings both before and during school. For the majority of these adolescents this responsibility was perceived as an everyday routine and they were "not bothered" by it unless it interfered with other social interactions.

Many of the adolescents described their involvement in preparing the sibling for school ranging from bathing, feeding, assisting with special equipment and assisting with transportation. One girl indicated that her parents ensured that the sibling was washed and fed and then her responsibilities began:

I have to put on his braces and his jacket, I have to help him up to his wheelchair and wait until the driver comes to pick him up.

Other adolescents stated that they helped their mothers in "getting (sibling) ready for school" by bathing or dressing the sibling once they had completed their own preparations.

Many of the siblings with spina bifida required special transportation to and from school because of their physical disabilities. The most common involvement of all the adolescents was assisting the sibling to the bus or taxi. The majority of the adolescents who attended the

same school as their sibling indicated that they preferred not to accompany their sibling on the bus or taxi. The few that did so stated that this was not a regular occurrence but rather was related to things like the weather or the time of year. The adolescents who did not share the same transportation as their sibling provided several reasons including personal preference and knowledge that the transportation was arranged for the sibling because of the disability. Some adolescents preferred to walk to school or take the regular school bus with their friends. One adolescent who was adamant about not getting on the special bus with her sibling tried to explain:

I never got on the bus with him, not once. I just don't want to. I won't, I won't, it just feels right wierd.

This adolescent further explained that she felt that she had enough responsibilities at home and expressed relief that there was a teacher's aide to help the sibling during school. She concluded by stating that:

during school everything is fine, it's just like a normal day in school. I don't have to help (sibling) with anything.

Some adolescents were required to assist their siblings during school. One girl stayed in the classroom with her sibling during the lunch break to assist her and

was rewarded in that her friends were also allowed to stay in the classroom. This was perceived by the adolescent as a benefit rather than a responsibility. One adolescent reported that her classes were sometimes interrupted if the sibling needed changing (diapers) or other assistance but also stated that she "didn't mind" these interruptions.

Harvey and Greenway (1984) found differences in the self-concept scores of children whose disabled sibling attended the same school as compared to the scores obtained by children whose sibling attended a special school. The self-concept scores of the adolescents were not specifically measured in the current study, and none of the adolescents had siblings who attended a special school (although some of the siblings did require the assistance of a teacher's aide). However, the adolescents, in describing experiences related to their developmental tasks, generally described their self-concept as favorable. None of the adolescents indicated that they possessed negative self-concept traits that could be attributed to the presence or absence of their disabled sibling in the school environment.

Those adolescents who attended the same school as their sibling or who were female tended to have more responsibilities for their siblings at school. The adolescents' reaction to this was generally one of

acceptance as long as they did not perceive their own social life at school as being affected. The adolescents exerted their own independence primarily through disassociating themselves from the sibling during the actual school time or through combining peer activities with sibling interactions.

Friends and peers

Having a brother or sister with spina bifida also influenced to some degree the relationship between the adolescents and their friends. For some, this included the selection of friends. As previously discussed, one girl in particular choose not to remain friends with an individual because of remarks made about her sibling. Most of the adolescents reported occasions whereby they had to explain their sibling's disability to their friends.

The findings of the current study concur with the suggestions of Powell and Ogle (1985) who acknowledged that siblings of children with disabilities have special concerns which are related to their friends. Powell and Ogle identified the four following areas in which siblings had concerns. They were: 1) informing their friends about the disabled child; 2) teasing; 3) the friends acceptance of the child; and 4) dating.

The adolescents indicated that they were often asked

about their sibling by new friends particularly at the beginning of the school year or when the family had moved to a new community. While the adolescents stated that they "didn't mind" answering questions, their responses to their friends questions were general in nature and often reflected a very basic understanding of spina bifida. The adolescents did feel that their friends were satisfied with the responses supplied to them.

One of the older adolescents had taken advantage of a public speaking opportunity at school to explain spina bifida to her peers. This girl perceived that the other students:

... needed to know something about it [spina bifida]. It's about time people understood what it was about because you never know what's going to happen, they can grow up and have a child with spina bifida and never have a clue.

The adolescents identified spina bifida as a congenital condition in that they were all aware that their sibling was "born with it". Many of the adolescents recognized that spina bifida as a "disorder of the spine" and that it could result in various degrees of paralysis. However, some of the adolescents had misconceptions regarding the source of the condition, i.e. one adolescent felt that spina bifida was related to a "hole in the stomach". None of the adolescents verbalized an

understanding of the complexity of the problems associated with spina bifida. The adolescents who mentioned the need for shunts [for hydrocephalus] did not identify the relationship between this and spina bifida or potential learning difficulties. Interestingly, while many of the adolescents indicated a responsibility for diapering their siblings, none identified bladder or bowel problems as being associated with spina bifida. Thus, adolescents who are often in a position to educate others regarding spina bifida may in fact be promoting incorrect or unrealistic information. One must also consider that perhaps the adolescents do not wish to elaborate on the specifics of spina bifida to their friends as this may tend to differentiate both their siblings and themselves from their friends. Thus, in an attempt to "normalize" both themselves and their siblings, the adolescents assign a minimal meaning to the siblings disability by discussing it in general terms.

The adolescents suggested that they did not need to defend the sibling to their friends because as one person explained: "friends understand, they don't ask questions." Others suggested that their friends also had relatives with various problems and therefore were more understanding or that the friends did not want to "hurt my feelings by asking or saying something about (Sibling)."

The need to explain spina bifida to others was often

associated with the need to defend the sibling. The adolescents did not have to defend the sibling to their friends but had experienced the need to defend their sibling to strangers and schoolmates. The adolescents had been approached by a variety of people, in a variety of situations, who commented on the sibling's condition, made uncharitable remarks or requested information. In defending the sibling the adolescent responded in different ways. One adolescent provided the following example:

There's a couple of girls in my class that think she's a burden and you've got to do everything for her, right. One time I hit a girl for saying it, I didn't mean to but, you know, they just came up to me and said God, your sister is such a burden, you've got to do everything for her, she can't do nothing for herself.

At a fast food restaurant frequented by adolescents, one girl described her reaction to remarks made about her sibling:

Some of the kids were saying look at the guy in the wheelchair, he's got funny shoes on so I had to tell them that it wasn't his fault and that it wasn't nice to say things like that.

Other adolescents described similar situations whereby they had to either defend their sibling or explain spina

bifida. Again, spina bifida was explained in basic, general terms using such phrases as he/she was "born with it" or is "paralysed."

Although some adolescents expressed resentment or anger towards the people who made remarks about their sibling, none of these reactions were displaced towards the sibling. The sibling was never blamed or felt to be in any way the source of the problem. The adolescents primarily defended the sibling because they [the adolescents] perceived the need to protect the sibling and to explain the condition and because they perceived other people as being insensitive to the needs of the sibling. In defending their sibling in public, the adolescents were also confirming their relationship with their sibling and demonstrating their own ability to communicate with others.

Personal maturation

Personal maturation refers to the overall developmental process that is ongoing during adolescence. The analysis of the data revealed a relationship between the process of development and the experiences associated with living with a sibling with spina bifida. One theme which emerged from the analysis of the data is that the adolescents had many unique experiences which may have contributed to the maturing process during this critical

stage of the life span. The experiences that were specifically related to having a brother or sister with spina bifida are unique to this population and were not shared by their peers or even their family in the same way.

The adolescents, particularly the older adolescents, demonstrated a maturity of attitudes related to several aspects of psychosocial development such as the ability to distinguish between health, illness and disability; the decision-making process and development of values for one's own life. The development of personal maturity in siblings of disabled children was discussed by Simeonsson and McHale (1981). The increased maturity of the siblings was considered to be one of the benefits of having a disabled sibling and may also be related to the further development of positive personality traits.

This maturity may be related to adolescents' increased involvement and participation in the care of the sibling at home or in school, increased parental expectations for this level of responsibility and the need to define spina bifida or defend the sibling to others. This maturation has culminated in the development of a philosophy of disability.

An analysis of the adolescents definitions of health or illness and the descriptions of spina bifida combined with the experiences related to living with the sibling

and explaining and defending their sibling's condition revealed that the adolescents had developed a philosophy of disability. The adolescents perceived health and illness as opposites and the presence of a physical disability did not automatically imply illness. The adolescents did not perceive their sibling with spina bifida as being ill and this may attribute to the adolescents descriptions of the sibling as being "normal." In fact, the adolescents also distinguished between hospitalizations for illness versus hospitalization for corrective surgery whereby the sibling was not perceived as being ill.

The need to defend the sibling and to explain spina bifida to others also facilitated the realization of the philosophy of disability. By witnessing others reactions to their sibling and recognizing that others needed to know about the condition the siblings learned something about human nature. In defending the disabled child and educating others, the adolescents were clarifying their position in relation to the meaning of their sibling's disability for themselves.

This philosophy of disability was also expressed through the adolescents' expectations of their siblings' ability to participate in everyday activities. The adolescents were willing to assist their siblings when necessary but also felt that the presence of the physical

disability need not hinder the sibling's involvement in specific activities.

The adolescents recognized that there were some limitations imposed upon their sibling as a result of having spina bifida. These limitations were related specifically to the physical nature of the disability and not related to mental or social abilities of the sibling. The adolescents suggested that their siblings have or may have difficulty with sports, transportation or future jobs (related to accessibility) but did not feel that their siblings had any problems at the current time in relation to making friends or being involved in activities that interested them. Thus, the philosophy of disability held by these adolescents is one which emphasizes the normalcy of the individual with the disability, with recognition that there are limitations often imposed upon the individual by the physical disability itself and by society in general.

Summary of the Discussion

The adolescents described strong family relationships which seem to be comparable to that of their friends. The adolescents were also clearly aware of their parents expectations of them. Above all, the adolescents attributed many of their attitudes and beliefs to the observations and experiences within their own family, a

family whose incorporation of a child with a physical disability was perceived as "normal". Thus, one would believe that in families where the child with the physical disability is treated as a "normal" child and in the same manner as the other children in the household, there exists a pattern of adaptation which the adolescent will adopt for him or herself. Duvall and Miller (1985) suggest that adolescents acquire their primary beliefs regarding major issues from the home environment and generally reflect parental values, whereas social issues are more determined by the peer group. Granted, each family deals with the experience of having a disabled child in unique ways and the adolescent will have individual responses to these experiences.

The adolescents' descriptions of their relationships with their siblings and their attitudes and beliefs about being the sibling of a physically disabled child reflect a process of development which has previously begun and is ongoing. None of the adolescents expressed any specific difficulty regarding their own development that was attributed to having a physically disabled sibling and in fact demonstrated a degree of personal maturity which reflects appropriate psychosocial development as well as previous adaptation at an earlier life stage.

The adolescents did not perceive themselves as being different from their friends nor did they think that their

friends perceived them as being any different because they had a sibling with spina bifida. The adolescents emphasized the normalcy of their sibling both to themselves and to others. In the process of doing this, the adolescents also recognized that there were some differences but these were minimized. Thus, the adolescents were not denying that differences did exist.

The majority of the adolescents in this study indicated that they were expected to assume increased responsibility for the physically disabled sibling in the home. Some of the adolescents were also expected to assume caretaking responsibilities for their sibling during school. This increase in responsibility was perceived by the adolescent to be related to being a teenager as well as related to the presence of a child with a physical disability in the home. This increased responsibility of the non-disabled sibling is well reported in the literature (Skrtic, Summers, Brotherton, & Turnbull, 1984; Kazak & Clark, 1986; Seligman, 1987).

Few of the adolescents indicated that there was a difference in the child-rearing practices employed by the parents towards the child with spina bifida and the other children in the home. Expressions of favoritism by the parents towards the child with spina bifida were occasionally observed by the adolescents, but the adolescents were able to rationalize this to their own

satisfaction.

Although the sibling relationship was not investigated in-depth in this study, some interesting findings were realized through the adolescents' comments. The adolescents regarded their siblings with affection, and demonstrated a protective attitude towards them.

The experience of living with and growing up with a brother or sister with spina bifida is the only experience that these adolescents can relate to. They do not recall or have experience with a family that does not include a disabled child; therefore, this situation is what is normal for them.

CHAPTER 6

Summary and Conclusions

The final chapter of this report begins with a summary of the study. The major limitations of the study are outlined. As well, implications for nursing practice, education, research, and theory development are identified.

Summary

Eleven adolescent siblings of children with spina bifida participated in an exploratory, descriptive study by describing their experiences at home, in school and with their peers as related to their own psychosocial development. The adolescents described many unique experiences related to being the sibling of a physically disabled child which may have influenced their own development. The adolescents were in the process of achieving the developmental tasks appropriate for their age and were satisfied with their own accomplishments. Many of the adolescents revealed a maturity in their attitudes towards their siblings, their families and their relationships with others. This maturity may be related to the experience of living with a sibling who has a physical disability.

Limitations

Two primary limitations were identified for this study; 1) the use of Duvall and Miller's (1985)

developmental tasks, and 2) the convenience sample.

The use of the developmental tasks as defined by Duvall and Miller (1985) is considered a limiting factor. While the use of the developmental tasks provided a necessary framework for the development of the interview guide and were invaluable in organizing data in relation to the first research question, they were of limited use in facilitating the analysis of data relating to the influence of having a sibling with a physical disability on adolescent development. The developmental tasks consider adolescent development within the context of the family as a unit and do not specifically address the individual sibling relationship which was of considerable importance to the findings of this study.

A second limitation of the study was the use of a convenience sample, rather than a theoretical sample, and the limited access to other potential participants. The literature identifies the problem of "multiple gatekeepers" in research involving children and adolescents (Faux, Walsh, and Deatrick, 1988). The participants in this study were limited to those adolescents whose families were identified for the study by the resource persons of the local spina bifida organization and the Children's Rehabilitation Centre. The parents had to agree to the study and the researcher had to rely on the parents to inform the adolescents about

the study. Therefore, there may be adolescents who could have contributed a great deal of information to this study but were unavailable to the researcher.

Implications for Nursing Practice and Education

The findings of the study have several implications for nursing practice and nursing education. Implications relate both to the needs of the individual adolescents and to the needs of the families who have a child with spina bifida. Nurses in both community and hospital settings need to assess the developmental status of all members of the family. The adolescents in this study demonstrated that the experiences associated with living with a child with a physical disability can have implications for their own lives. At the completion of a developmental assessment the nurse would be able to identify the concerns and needs unique to each adolescent and thus implement an appropriate plan of care.

It is also important for nurses to recognize that implications for adolescents change when the sibling is hospitalized. Hospitalization of a child is usually considered a crisis period for the child and the parents. The adolescents in this study revealed that their sibling's hospitalization had an impact upon their responsibilities at home and/or influenced the sibling relationship.

Nurses also have a role in providing more information to adolescents regarding the nature of spina bifida. The adolescents need to acquire an understanding of the broad implications of spina bifida both for themselves and their siblings. Adolescents are frequently asked questions by others about spina bifida and may be giving incomplete or false information which may in fact not be beneficial to the child with spina bifida. Adolescents need more information about spina bifida in order to make future decisions for themselves, particularly in the area of reproduction. The adolescents have a lack of knowledge related to the genetic implication of a positive family history for themselves. Some adolescents may need to be referred for genetic counselling.

The findings of the study also support the need for education of the general public about the nature of spina bifida and the abilities of children with spina bifida. Many of the adolescents had to defend their sibling when others verbalized their lack of knowledge or their insensitivity regarding the disability. Through the education of the general public, it would be anticipated that the need to defend the sibling would diminish and there would be a greater acceptance of the disabled child in the community.

Nurses are also in a position to provide anticipatory guidance to parents who are raising both disabled and non-

disabled children in the same household. Parents who are often concerned about the implications of having a physically disabled brother or sister on other siblings can be appropriately advised on the basis of individual developmental assessments. Parents should be prepared to anticipate adolescent concerns regarding their own responsibilities for the sibling, either at home or at school. Parents can also anticipate questions regarding the future for their siblings and should be encouraged to discuss with all family members issues related to present and future needs of the care of the individual with spina bifida. The findings of this particular study could be used with parents who are concerned with the development of their non-disabled child. The parents could be reassured that siblings of children with spina bifida do seem to meet the appropriate developmental tasks for their age and that no major negative effects were noted in the adolescents in this particular study.

There is a potential need for the establishment of a support group for siblings in which nursing should be involved. Nurses would be able to promote the communication among adolescents who share similar life experiences. The adolescents indicated that they would have advice that could be shared with others. The mutual sharing of experiences of the adolescents may enhance continuation of successful achievement of succeeding

developmental tasks of adolescents and adulthood.

The findings of this study also have implications for nursing education. In a world of rapidly advancing medical technology and increased social awareness of the needs of children with disabilities and their families, nurses need to be prepared to provide comprehensive care in a variety of settings. Nurse educators should have a greater awareness of current research in this area and integrate research findings in their teaching and nursing practice. Future generations of nurses need to be well prepared in all aspects of growth and development to compliment technological advancements. The integration of knowledge of growth and development with clinical skills can only improve the provision of comprehensive care to children with physical disabilities and their families.

Implications for Research and Theory Development

Further research is warranted to investigate the value of exposing siblings to the experience gained through participation in the study. During the interview, many adolescents stated that they appreciated the opportunity to tell their stories and the interest shown them by health professionals such as the researcher. The opportunity to express themselves to attending adults may have a positive influence on the development during adolescence.

Further studies which investigate the sibling relationship (when one child has a physical disability) and its impact upon the development of the siblings are recommended. The current study was limited in the depth and scope of the data pertaining to the sibling relationship. Yet, the sibling relationship was identified as a contributing factor to the development of adolescents.

Parents often expressed concern regarding the implications of having a physically disabled child for other children in the family. A study which compares the parental and sibling perceptions of these implications should be initiated.

Further studies, similar to the one completed would validate the findings and contribute to the conceptual knowledge base thus facilitating the development of a framework that would be useful in applying the nursing process in a family centered manner for children with spina bifida and their families.

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APPENDIX A

Letter to the President of the Newfoundland and Labrador
Association for Spina Bifida and Hydrocephalus

Dear Mrs. Edney:

I am a graduate student currently registered in the School of Nursing, Graduate Program in Maternal/Child Nursing at Memorial University of Newfoundland. A partial requirement for the degree of Master of Nursing is a research study. This letter is to explain the purpose of my study and to seek your cooperation in selecting children who might be included in the study's sample.

The immediate purpose of this study is to explore the perceptions of adolescent siblings of physically handicapped children in relation to their ability in meeting prescribed developmental tasks. It is in determining whether or not the adolescents perceive themselves as achieving these tasks can the nursing profession provide anticipatory care for the adolescent and provide care for the family unit. Thus, the ultimate purpose of the study is to contribute to the knowledge that could be used by nurses and other health care workers to facilitate optimal development of adolescent siblings of physically handicapped children.

This is a qualitative research study which will involve interviewing the adolescents. The interviews will be semi-structured to gain specific information about how the adolescents feel they are meeting developmental tasks appropriate to their age group. Open ended questions will also be used to gain insight into some of the experience these adolescents have in relation to being a sibling to a handicapped child and its perceived implications on their own development. The content of the interviews will be analyzed to describe and identify the similarities and differences in the responses of the adolescents. Areas of development in which the adolescents perceive themselves as achieving or have difficulty in achieving will be explored. Following the collection and analysis of the data, all tapes or notes will be destroyed. There will be no names or distinguishing characteristics identified in the report. The methods for data collection and analysis will be reviewed by the Ethical Review Committee of the School of Graduate Studies at Memorial University of Newfoundland. I will confirm the approval of this committee to you prior to the commencement of data collection.

I am requesting that the Association identify from its records, families in which there is a child with spina bifida and a non-affected adolescent sibling (between the ages of 13 to 18 years) that could be included in the

study. I would ask that you make the initial contact with these families to sign a release of name form (attached) so that you can then provide me with their names and telephone numbers. I would then contact each family selected to further explain the study, answer any questions and arrange a time to interview the adolescent.

I will also be forwarding a similar request to the Children's Rehabilitation Center to obtain a comprehensive sample population. On completion of the study, a report of the findings will be forwarded to the Association.

I hope you will have a favorable response to this request. Your help in identifying families for inclusion in this study is vital. I am available to provide further information and to answer any questions that you may have. I look forward to a reply at your earliest convenience.

Sincerely,

Catherine Royle
23 Wexford Street
St. John's, Newfoundland
Telephone: 754-1160

APPENDIX B

Letter to the Director of Nursing, Children's
Rehabilitation Center

Dear Mrs. Coultas:

I am a graduate student currently registered in the School of Nursing, Graduate Program in Maternal/Child Nursing at Memorial University of Newfoundland. A partial requirement for the degree of Master of Nursing is a research study. This letter is to explain the purpose of my study and to seek your cooperation in selecting children who might be included in the study's sample.

The immediate purpose of this study is to explore the perceptions of adolescent siblings of physically handicapped children in relation to their ability in meeting prescribed developmental tasks. It is in determining whether or not the adolescents perceive themselves as achieving these tasks can the nursing profession provide anticipatory care for the adolescent and provide care for the family unit. Thus, the ultimate purpose of the study is to contribute to the knowledge that could be used by nurses and other health care workers to facilitate optimal development of adolescent siblings of physically handicapped children.

This is a qualitative research study which will involve interviewing the adolescents. The interviews will be semi-structured to gain specific information about how the adolescents feel they are meeting developmental tasks appropriate to their age group. Open ended questions will also be used to gain insight into some of the experience these adolescents have in relation to being a sibling to a handicapped child and its perceived implications on their own development. The content of the interviews will be analyzed to describe and identify the similarities and differences in the responses of the adolescents. Areas of development in which the adolescents perceive themselves as achieving or have difficulty in achieving will be explored. Following the collection and analysis of the data, all tapes or notes will be destroyed. There will be no names or distinguishing characteristics identified in the report. The methods for data collection and analysis will be reviewed by the Ethical Review Committee of the School of Graduate Studies at Memorial University of Newfoundland. I will confirm the approval of this committee to you prior to the commencement of data collection.

I am requesting that the Nursing Coordinator of Outpatient Services identify, from the records, families in which there is a child with spina bifida and a non-affected adolescent sibling (between the ages of 13 to 18

years) that could be included in the study. I would ask that she make the initial contact with these families to sign a release of name form (attached) so that you can then provide me with their names and telephone numbers. I would then contact each family selected to further explain the study, answer any questions and arrange a time to interview the adolescent.

I will also be forwarding a similar request to the Newfoundland and Labrador Association for Spina Bifida and Hydrocephalus to obtain a comprehensive sample population. On completion of the study, a report of the findings will be forwarded to the Children's Rehabilitation Center.

I hope you will have a favorable response to this request. Your help in identifying families for inclusion in this study is vital. I am available to provide further information and to answer any questions that you may have. I look forward to a reply at your earliest convenience.

Sincerely,

Catherine Royle
23 Wexford Street
St. John's, Newfoundland
Telephone: 754-1160

APPENDIX C

Release of Name Form

I have been asked to consent to my name and telephone number being released to Catherine Royle who is conducting a study to explore the development of adolescent siblings of physically handicapped children. Catherine Royle is a registered nurse who is enrolled in the School of Graduate Studies (School of Nursing) at Memorial University of Newfoundland.

I understand that a tape recorded interview will be set up by the researcher with my adolescent son/daughter at the convenience of our family and by appointment. This interview may take place in our home, if that is the choice of the adolescent.

I understand that my son/daughter is under no obligation to participate in the study and may withdraw at any time. My son/daughter's special permission for the use of a tape recorder during the interview will be requested. Withdrawal or refusal to participate in the study will not alter the nursing services we are receiving from the Children's Rehabilitation Center in St. John's, nor the support of the Newfoundland and Labrador Association for Spina Bifida and Hydrocephalus.

I understand that I will be contacted by the researcher, Catherine Royle, who will explain the purpose of the study, answer any questions that I may have and arrange a convenient time for an appointment.

Signature of Parent

Name

Telephone Number

Researcher: Catherine Royle
23 Wexford Street
St. John's, Nfld.
A1B 1W6
Telephone: 754-1160

APPENDIX D

Explanation to Parents

Mr. and Mrs. _____, my name is Catherine Royle and I am a registered nurse who is also a graduate student in the School of Nursing at Memorial University of Newfoundland. I am conducting a research project to meet the requirements for a Master of Nursing degree.

The purpose of this study is to describe how the adolescent brothers and sisters of children who are physically handicapped meet the developmental tasks appropriate for their age group. It is anticipated that this study will provide new information about siblings of physically handicapped children for nurses and other health professionals that would be beneficial in providing better care.

Your participation in the study will be in permitting your son/daughter to be included in the study sample. You will also be asked specific questions regarding the age and number of children in the household. Your son's/daughter's participation in the study will involve two tape recorded interviews, each being approximately one hour in duration. The interview will include general questions about the adolescent's thoughts about various aspects of their own development.

Neither you or your son/daughter, are under any obligation to participate in the study or answer any specific question and may withdraw at any time. If you enter the study and later choose to withdraw or not participate in the study, it will not affect the care you are receiving from the Children's Rehabilitation Center or the Newfoundland and Labrador Association for Spina Bifida and Hydrocephalus.

I would like permission to ask _____ (child's name) some questions regarding his / her own development. You may review the general questions I will be including in the interview with your son/daughter. A copy of the kinds of questions will be provided prior to the beginning of the study interview.

All information will remain confidential. Following analysis of the data, all information collected during the tape-recorded interview will be destroyed. Neither the parents nor the children or distinguishing characteristics will be identified in any report. A final report of the study will be made available to the Children's

Rehabilitation Center and the Newfoundland and Labrador
Association for Spina Bifida and Hydrocephalus.

Thank you, in advance, for your cooperation.

Catherine Royle
23 Wexford Street
St. John's, Newfoundland
A1B 1W6

754-1160

APPENDIX E

Consent Form

On behalf of _____ (child's name), I _____, the parent of the child, consent to my participation and my child's participation in the study exploring the development of adolescent siblings of physically handicapped children.

I understand that my participation in the study will involve answering specific questions about the age and number of children in the family. _____ (child's name) participation in the study will be in the form of answering general questions about their own development during a tape-recorded interview. _____ (adolescent's name) special permission for the use of a tape recorder during the session will be requested.

The interview will take place in the family home, if desired by _____. There will be one or two interviews, each being a maximum of one hour in duration.

I understand that we, nor the child are under any obligation to participate in the study and may withdraw at any time. Also, if we choose to withdraw or refuse to participate in the study, the care we receive from the Children's Rehabilitation Center and/or the Newfoundland and Labrador Association for Spina Bifida and Hydrocephalus will not be affected.

All information will remain anonymous. Following analysis of the tape recorded interview, the tapes will be destroyed. Neither my name or identifying characteristics or my children's names or identifying characteristics will be included in the report.

I acknowledge that a copy of this consent form will remain with me.

Signature of adolescent

Signature of Parent

Signature of Researcher

Date

APPENDIX F

Demographic Data (from parents)

Number of children in the household _____

Ages of the children in the household _____

How old is the child with spina bifida? _____

Is the child with spina bifida male or female? _____

Is the adolescent sibling older or younger than the child with spina bifida? _____

Is the adolescent sibling male or female? _____

APPENDIX G

Guide to Interview Topics with the Adolescent

Demographic data:

age: _____

sex: _____

birth order: _____

General questions:

Describe for me a typical school day.

Describe for me a typical weekend.

Tell me about yourself.

Questions related to the developmental tasks.

What are some of the things girls your age enjoy, or should be involved in?

What are some of the things that boys your age enjoy, or should be involved in?

What do you think boys and girls your age enjoy doing together?

What is the best thing about being a teenager (m/f)?

What do you like the least about being a teenager?

Are you satisfied with being a teenage girl (boy) now?

What do you look forward to the most in becoming an adult?

Do you belong to a group of friends?

Do you have both male and female friends?

What are some of the things that you do together?

How is this different than when you were younger?

How well do you judge yourself in making friends?

Do you have a separate group of friends in the neighborhood than you do in school?

How would you describe your relationship with your friends?

How do your friends get along with (.....)?

Have you ever had to explain spina bifida to them?

Do you think that having a brother or sister makes you any different than your friends?

Do you ever think that your friends or anyone might think that you are different because you have a brother or sister with spina bifida?

Have you ever had an occasion when you had to choose between two friends?

Do you ever argue with your friends? about what.

How would you describe your relationship with your parents?

What do you think that your parents expect of you now that you are a teenager?

What do they expect of your friends?

Do you think that your parents expect more of you than of your brother or sister with spina bifida? In what way?

How do you feel about your parents expectations?

What are some things that you depend upon your parents for?

What are some decisions that you like to make for yourself?

What are some decisions that your parents should make for you?

What are some things that you should decide on together?

What grade are you in school?

What kinds of interests do you have outside of school?

What are your plans for when you finish high school?

Have you thought about a career?

Do you think that having a brother or sister with spina bifida has had an influence on your career choices?

What kinds of careers are girls interested in? boys?

What are your responsibilities in the home? (ie chores)

What are the benefits to being a member of this family?

Do you think that men and women have different roles in the family? explain.

Is dating important to teenagers? Why?

When should a boy and girl start to date? to go steady?

Have you ever had a "crush" on somebody?

What is the difference between having a crush on somebody and being in love and wanting to get married?

Why do you think most people get married?

What is your opinion of marriage?

Would you like to get married and have children?

Do you think that your ideas about having children are influenced by having a brother or sister with spina bifida

What does health mean to you?

What kinds of things do you do to keep yourself healthy?

What are some things that you might do that are not healthy?

Can you describe for me a situation where you had to use some of the physical skills that you have learned.

What does it mean to be "masculine"? "feminine"?

Have you noticed any changes in your body since you've become a teenager?

How does this compare with your friends?

What do you think these changes mean?

Have there been any changes in your lifestyle that are related to the changes in your body?

What does maturity mean to you?

What is the difference between what you are now and what you think you will be when your body has matured?

Do you belong to any groups or organizations?

Do you volunteer to do things or projects at school, or at home, or with your friends?

What would you do if:
you were invited to a party that you didn't want to go to?

you could only invite three friends to your house and you had six friends in your group?

your parents disagreed with you about the clothes you were wearing to the party?

you found out that your friends were invited to a party but you weren't?

How do you earn money?

What do you spend money on?

What do you think is the purpose of having laws?

Do you think the laws are good?

Can you name some laws that people in general should follow?

How would you describe yourself?

What goals have you set for yourself?

What things in life are important to you ?

Who are the most important people in your life?

What do you do if somebody discourages you or if you are disappointed about something?

What do you think about social issues such as:
drinking and driving
sex education in school
teenage pregnancy.

If you could have three wishes , what would they be?

APPENDIX E

Consent Form

On behalf of _____ (child's name), I _____, the parent of the child, consent to my participation and my child's participation in the study exploring the development of adolescent siblings of physically handicapped children.

I understand that my participation in the study will involve answering specific questions about the age and number of children in the family. _____

(child's name) participation in the study will be in the form of answering general questions about their own development during a tape-recorded interview.

_____ (adolescent's name) special permission for the use of a tape recorder during the session will be requested.

The interview will take place in the family home, if desired by _____. There will be one or two interviews, each being a maximum of one hour in duration.

I understand that we, nor the child are under any obligation to participate in the study and may withdraw at any time. Also, if we choose to withdraw or refuse to participate in the study, the care we receive from the Children's Rehabilitation Center and/or the Newfoundland and Labrador Association for Spina Bifida and Hydrocephalus will not be affected.

All information will remain anonymous. Following analysis of the tape recorded interview, the tapes will be destroyed. Neither my name or identifying characteristics or my children's names or identifying characteristics will be included in the report.

I acknowledge that a copy of this consent form will remain with me.

Signature of adolescent

Signature of Parent

Signature of Researcher

Date

APPENDIX F

Demographic Data (from parents)

Number of children in the household _____

Ages of the children in the household _____

How old is the child with spina bifida? _____

Is the child with spina bifida male or female? _____

Is the adolescent sibling older or younger than the child with spina bifida? _____

Is the adolescent sibling male or female? _____

APPENDIX G

Guide to Interview Topics with the Adolescent

Demographic data:

age: _____
sex: _____
birth order: _____

General questions:

Describe for me a typical school day.

Describe for me a typical weekend.

Tell me about yourself.

Questions related to the developmental tasks.

What are some of the things girls your age enjoy, or should be involved in?

What are some of the things that boys your age enjoy, or should be involved in?

What do you think boys and girls your age enjoy doing together?

What is the best thing about being a teenager (m/f)?

What do you like the least about being a teenager?

Are you satisfied with being a teenage girl (boy) now?

What do you look forward to the most in becoming an adult?

Do you belong to a group of friends?

Do you have both male and female friends?

What are some of the things that you do together?

How is this different than when you were younger?

How well do you judge yourself in making friends?

Do you have a separate group of friends in the neighborhood than you do in school?

How would you describe your relationship with your friends?

How do your friends get along with (.....)?

Have you ever had to explain spina bifida to them?

Do you think that having a brother or sister makes you any different than your friends?

Do you ever think that your friends or anyone might think that you are different because you have a brother or sister with spina bifida?

Have you ever had an occasion when you had to choose between two friends?

Do you ever argue with your friends? about what.

How would you describe your relationship with your parents?

What do you think that your parents expect of you now that you are a teenager?

What do they expect of your friends?

Do you think that your parents expect more of you than of your brother or sister with spina bifida? In what way?

How do you feel about your parents expectations?

What are some things that you depend upon your parents for?

What are some decisions that you like to make for yourself?

What are some decisions that your parents should make for you?

What are some things that you should decide on together?

What grade are you in school?

What kinds of interests do you have outside of school?

What are your plans for when you finish high school?

Have you thought about a career?

Do you think that having a brother or sister with spina bifida has had an influence on your career choices?

What kinds of careers are girls interested in? boys?

What are your responsibilities in the home? (ie chores)

What are the benefits to being a member of this family?

Do you think that men and women have different roles in the family? explain.

Is dating important to teenagers? Why?

When should a boy and girl start to date? to go steady?

Have you ever had a "crush" on somebody?

What is the difference between having a crush on somebody and being in love and wanting to get married?

Why do you think most people get married?

What is your opinion of marriage?

Would you like to get married and have children?

Do you think that your ideas about having children are influenced by having a brother or sister with spina bifida

What does health mean to you?

What kinds of things do you do to keep yourself healthy?

What are some things that you might do that are not healthy?

Can you describe for me a situation where you had to use some of the physical skills that you have learned.

What does it mean to be "masculine"? "feminine"?

Have you noticed any changes in your body since you've become a teenager?

How does this compare with your friends?

What do you think these changes mean?

Have there been any changes in your lifestyle that are related to the changes in your body?

What does maturity mean to you?

What is the difference between what you are now and what you think you will be when your body has matured?

Do you belong to any groups or organizations?

Do you volunteer to do things or projects at school, or at home, or with your friends?

What would you do if:

you were invited to a party that you didn't want to go to?

you could only invite three friends to your house and you had six friends in your group?

your parents disagreed with you about the clothes you were wearing to the party?

you found out that your friends were invited to a party but you weren't?

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